FACTORS RELATING TO EMOTIONAL DISTRESS AFTER STROKE

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ABSTRACT

Emotional distress is common after stroke and has a negative impact on rehabilitation outcome. The aim of this thesis was to identify factors relating to emotional distress after stroke to inform future interventions. This thesis developed a theoretical framework to guide the study of emotional distress and included stroke and demographic characteristics, background information, disability (personal and extended activities of daily living and aphasia) and psychosocial factors (coping, locus of control and social support). This thesis consisted of three studies.

The first study developed and validated the Stroke Cognitions Questionnaire Revised (SCQR), as previous studies used cognitions assessments not appropriate for this population. The SCQR assesses the frequency of positive and negative stroke-related cognitions. The scale was developed from treatment notes of depressed stroke patients. The scale had high internal consistency, inter-rater and test retest reliability, and concurrent validity. Depression (Beck Depression Inventory; BDI) was characterized by a preponderance of negative cognitions and, to a lesser extent, a decrement in positive cognitions. This supports the cognitive model of depression.

The second study evaluated factors that predicted the severity of depression in a sample of 112 depressed patients recruited to a randomised controlled trial of cognitive behaviour therapy between one and six months post-stroke. Communication impairment (Sheffield Screening Test for Acquired Language Disorders; SST) at recruitment was predictive of severe depression (BDI) at recruitment. Patients with greater communication impairment (SST) and a more external locus of control (Recovery Locus of Control Scale; RLOC) at recruitment

were more likely to remain depressed at six months follow-up. Patients who remained depressed at follow-up were more severely depressed at recruitment.

The main study of this thesis evaluated the proposed theoretical framework of emotional distress. In a prospective longitudinal study, 100 patients were recruited from hospital at one month post-stroke and assessed on communication (SST), personal activities of daily living (ADL; Barthel Index), distress (Visual Analogue Mood Scales, Visual Analogue Self-Esteem Scale and Stroke Aphasic Depression Questionnaire). Patients who were not aphasic completed additional assessments of distress (Hospital Anxiety and Depression Scale, Beck Depression Inventory II), recovery locus of control (RLOC), coping (Brief COPE) and cognitions (SCQR). Patients were reassessed on the same measures at six months (n=92), in addition to extended ADL (Extended ADL Index) and social support (Significant Others Scale; SOS). Communication impairment and dependence in personal ADL were predictive of distress at one month. Communication impairment and dependence in extended ADL were predictive of distress at six months. In non aphasic patients, externality of locus of control was also predictive of distress at one months and six months and actual social support was predictive of distress at six months. The relationship between coping and distress was mediated by locus of control. Distress remained persistent at six months post-stroke.

The factors found to predict distress (communication impairment, recovery locus of control and activity level) will help identify patients at risk of distress. Also, this demonstrates the need to include aphasic patients. The risk factors are amenable to psychological intervention, such as cognitive behaviour therapy and coping skills training. Future research should evaluate the proposed interventions.

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1 LITERATURE REVIEW

1.1 Stroke

1.1.1 What is a stroke?

Stroke refers to damage to the brain or spinal cord caused by abnormality of the blood supply (Caplan, 2000). Over 2000 years ago, Hippocrates first recognised and described *'stroke of apoplexy'* as the sudden onset of paralysis. In the mid 17th century, Jacob Kepfer found from post mortem studies that apoplexy was associated with bleeding in the brain or blockage in a cerebral artery. The accepted definition of stroke is from the World Health Organisation: ***'A syndrome of rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than vascular origin'*** (Hatona, 1976 p.541). This excludes transient ischaemic attack (TIA), which is when symptoms resolve within 24 hours. It also excludes subdural haematoma and haemorrhage or infarction attributable to trauma, infection or tumour. This section will outline what a stroke is, the effects that stroke can have, classifications of stroke and the incidence and prevalence of stroke.

A stroke, or cerebrovascular accident, is a clinical syndrome rather than a homogeneous entity. It is important to distinguish between different types of stroke as each can have varying consequences requiring different treatment. There are two main types of stroke, ischaemic stroke and haemorrhagic stroke (Caplan, 2000).

Ischaemic stroke (about 80% of strokes) – caused by a blockage in an artery supplying blood to the brain, depriving brain tissue of oxygen and nutrients. Three mechanisms can cause ischaemia: thrombosis – the lumen of an artery supplying the

brain is narrowed or occluded, usually by a blood clot; embolism – a blood clot originating elsewhere in the body travels through the vascular system and becomes lodged in an artery supplying the brain: decreased systemic perfusion – reduced blood flow to brain tissue resulting from low systemic perfusion pressure. Ischaemic stroke results in temporary or permanent (infarction) tissue damage. The degree of damage is determined by the location of the affected arteries, the length of time blood flow is impeded and resistance of brain areas to ischaemia. Lacunar infarctions, or smaller strokes, occur in subcortical structures when blood flow is steadily interrupted.

Haemorrhagic stroke (about 20% of strokes) – bleeding into the brain and extravascular spaces within the cranium. Brain tissue is torn when blood is released under higher pressure; a haematoma (blood clot) forms preventing blood flow to surrounding tissue and causes swelling in adjacent brain tissue. Biochemical changes can damage brain tissue. The two main types of cerebral haemorrhage are: intracerebral haemorrhage – bleeding directly into the brain substance, usually caused by hypertension and subarachnoid haemorrhage – bleeding into the vascular bed under the arachnoid covering of the brain, often due to a ruptured intracranial aneurysm or bleeding from an arteriovenous malformation. The extent of damage caused is contingent on the location, speed, pressure and volume of the bleed.

The distinction between cerebral infarction and primary intracerebral haemorrhage is most accurate when a computerised tomography (CT) scan is performed seven to 14 days post-stroke (Bamford, 1991), as CT scans are unable to distinguish between a haemorrhage and an infarct at about a week or more after stroke. CT scans are

limited in that they are less reliable at diagnosing subarachnoid haemorrhage. Magnetic resonance imaging (MRI) scans are more sensitive than CT scans at detecting acute infarcts and imaging brainstem and cerebellar infarcts, haemorrhages and spinal cord strokes. MRI scans are also superior at identifying the three-dimensional location of the lesion. However, CT scans are performed more routinely as they are less expensive, more readily available and quicker to perform, which is advantageous with ill patients.

The consequences of stroke can be diverse according to the locality and extent of brain damage, and effects can be temporary or permanent, mild or severe. The effects of a stroke can be divided into broad categories: motor deficits include hemiparesis (weakness of one side of the body), dysphagia (swallowing difficulties), dysarthria (slurred speech due to muscle weakness or paralysis) and incontinence; sensory problems such as loss of sense of touch, and hemianopia; cognitive problems including aphasia (language impairment), difficulty with reasoning, planning, concentration, memory and perception, and apraxia (difficulty with the production of purposive movements); mood changes including depression, anxiety, anger and emotional lability. An alternative approach to considering the effects of stroke is that of the World Health Organisation, which considers the impact of impairment on everyday life. This distinguishes between *impairment*, which is the physical or psychological lesion (e.g. hemianopia, hemiplegia), *activity limitation,* which is the functional consequence of impairment (e.g. inability to walk), and *participation restriction*, which is the disadvantage caused by the impairment and disability (e.g. have to give up work).

1.1.2 Classification of stroke

'Stroke' refers to a heterogeneous group of disorders with similar clinical manifestations (Bamford, 1991). Different subtypes are associated with different causes, symptoms and consequences. Diagnosis and classification of stroke is inconsistent across studies and inclusion and exclusion criteria vary. Diagnosis is not 100% accurate, with 30%-50% of patients with a clinically definite stroke not showing relevant abnormalities on an acute CT scan (Bamford, 1991). In 20% of transient ischaemic attacks there will be signs of ischaemia on the CT scan. The reliability of clinical diagnosis can be reduced by poor history, unusual signs or symptoms, and progressing neurological signs.

Classification approaches which rely on diagnostic technology (e.g. CT scans) are expensive and time consuming, and facilities vary across hospitals (Lindley et al, 1993). One possible classification is anatomical according to the site of occlusion – internal carotid artery, middle cerebral artery, anterior cerebral artery, posterior cerebral artery and basilar artery. However, it is difficult to determine the site of occlusion without an invasive vascular investigation (Bamford, 1991). A simple and widely applicable classification of cerebral infarcts which can accommodate disparate clinical practices has been suggested (Bamford, Sandercock, Dennis, Burn, & Warlow, 1991). The benefits of using this system are that it allows more accurate prediction of prognosis and better planning of patient management.

Bamford (1991) noted there is a different natural history for anterior (carotid) circulation infarcts (ACIs) and posterior (vertebrobasilar) infarcts. Furthermore, ACIs could be subdivided into those involving both cortical and subcortical structures, for example, those producing hemianopia, hemiplegia and higher cerebral

dysfunction (total anterior circulation), and those with more restricted deficits associated with just cortical dysfunction (partial anterior circulation). The Bamford classification divides strokes into four subtypes based on the size and site of infarct. If intracerebral haemorrhage has not been ruled out the stroke is referred to as a syndrome rather than an infarct. The classification system is shown in Figure 1.1. This is based on clinical findings at the point of maximum deficit following a single stroke. The advantages of this classification are that it can be performed quickly at bedside, patients with a normal CT scan can be classified, and each subtype has a relatively predictable prognosis (Lindley et al, 1993). It can be easily applied to most patients, allowing studies to be compared. The classification was developed in a community study in which not all patients were assessed in the acute phase of stroke (Bamford et al, 1991). Moderate to good inter-observer agreement was found in patients assessed within the first 10 days after stroke (Lindley et al, 1993). The classification correctly predicted site and size of infarct in 75% of patients, with misclassifications attributable to some patients being assessed up to three months after stroke (Mead, Lewis, Wardlaw, Dennis, & Warlow, 2000). The following proportions can be expected for first stroke (Wolfe, 1996): cerebral infarction-76% (TACS 15%; PACS 56%; POCS 8%; LACS 20%; unclassified 1%), primary intracererbal haemorrhage 10%, subarachnoid haemorrhage 4% and unknown 10%. Worst prognosis has been found for TACS patients (Bamford et al, 1991; Pittock et al, 2003). The Bamford classification probably underestimates premorbid silent cerebrovascular disease and small vessel disease, but it is currently the best classification available (Wolfe, 1996).

Figure 1.1 Bamford classification of stroke (Bamford, 1991; Bamford et al, 1991)

Classification	Signs and Symptoms
TACI: Total anterior circulation infarct Ischaemia in deep and superficial territories of middle cerebral artery (MCA).	A combination of 3 of the following - Higher cerebral dysfunction (such as dyscalculia, inattention, visuo-spatial disorder) - Homonymous visual field deficit - Motor and/or sensory deficit of at least 2 of face, arm and leg
PACI: Partial anterior circulation infarct More restricted cortical infarct to upper or lower division of MCA, including isolated infarcts in anterior cerebral artery territory.	- Two out of three components for TACI or - Higher cerebral dysfunction alone or - Motor/sensory deficit more restricted than LACI (e.g. confined to one limb)
POCI: Posterior circulation infarct Infarcts associated with brainstem, cerebellum or occipital lobes. Vertebrobasilar artery territory.	One or more of: - Bilateral motor and/or sensory deficit - Ipsilateral cranial nerve palsy with contralateral motor and/or sensory deficit - Cerebellar dysfunction without ipsilateral motor deficit - Isolated homonymous visual field defects
LACI: Lacunar infarction Small lacunar infarcts in basal ganglia or pons.	- Pure motor deficit - Pure sensory stroke - Pure sensorimotor stroke - Ataxic hemiparesis

1.1.3 Incidence and prevalence of stroke

In England and Wales 110,000 people suffer a first stroke each year, and 30,000 people go on to have a further stroke (Department of Health, 2001). The incidence of a first stroke is 2.4 per 1000 per year (Wolfe, 1996). The estimated prevalence of stroke, that is the number of sufferers in the population, is 300-700 per 100,000 of the general population (Wade, Langton Hewer, Skilbeck, & David, 1985). The

recurrence rate is 5% per year, and this is higher in the first weeks and months proceeding stroke (Warlow, 1998). Within five years the risk of recurrence is 30%-43% (RCP, 2004). Stroke is the third most common cause of death in the UK and other developed countries, and the single biggest cause of severe disability (Wolfe, Rudd, & Beech, 1996). Stroke accounts for 10-12% of deaths in industrialised countries, with 88% of deaths occurring in those over 65 years old (Wolfe, 1996). Around 30% of patients who have a first stroke die within a month (Department of Health, 2001), and of those alive at six months, one-third are dependent on others for activities of daily living (Warlow, 1998). Case fatality rates depend on age and health status of the population, and averages conceal variations due to stroke subtypes, severity and pre-stroke disability (Warlow, 1998). The relative risk of dying is about twice that of the general population, and this risk remains for several years (Hankey, 2002).

The incidence of stroke rises exponentially with age (Wolfe, 1996), with age-specific rates rising from 60-80/100,000 aged 45-54, to 600-1200/100,000 aged 65-74, up to 4000/100,000 aged 85 years and above (Wade et al, 1985). Around 10,000 people under 55 years and 1,000 people under 30 suffer a stroke each year (OPCS, 1998). The increasing age of the population indicates that the burden of stroke is unlikely to subside. A hospital-based study found older patients (over 75 years old) had greater disability following acute stroke and higher mortality than those under 75 (Sharma, Fletcher, & Vassallo, 1999). This is probably related to the pre-existing morbidity in older patients. The lifetime risk of a stroke is slightly higher in men, but lifetime risk of dying from a stroke is greater for women, probably attributable to the older age at which women are likely to suffer a stroke (Bonita, 1992).

Subarachnoid haemorrhage (SAH) is relatively uncommon, with approximately 8,000 new cases occurring in the UK each year (Stroke Association, 2000). The incidence of SAH is 6-12 per 100,000 per year, constituting 6% of first stroke (RCP, 2004). Fatality rates for SAH are high, with about one-third of patients dying immediately or shortly after hospitalisation, and a further third dying within a few weeks (Stroke Association, 2000). SAH most commonly occurs in middle-aged people, with a female to male ratio of 3:2.

1.1.4 Stroke recovery and long-term outcome

There is a lack of precise definition of recovery, and therefore no consensus on the best method for characterising stroke recovery (Duncan, Min Lai, & Keighley, 2000). Neurological function begins to improve in the first few days post stroke with improvement most rapid within the first three months, slowing between six months and one year, with little gains between one and two years (Hankey, 2002). Duncan et al (2000) reported similar recovery patterns for functional abilities and physical function, although many who were independent in activities of daily living had residual neurological impairments and did not return to previous levels of functioning. The proportion of patients who 'recovered' was dependent on the definition of recovery. Most spontaneous recovery occurs in the first three months after stroke, with some improvement up to six months, and little change after this point (Ebrahim & Harwood, 1999).

1.1.5 Cost of stroke

Stroke can have a major financial impact on the survivor and their carer through loss of income, modifications to housing, and the cost of private support. A large proportion of the NHS budget is spent on treating stroke patients due the significant

effects on disability and ill-health (Carroll, Murad, Eliahoo, & Majeed, 2001). Costs include hospitalisation, daily treatments and outpatient resources (e.g. occupational therapy, physiotherapy and home nursing). Stroke is a major consumer of health care and hospital resources, although the long-term costs to the community in terms of continuing care are unknown (Wade et al, 1985). An economic model estimated that for the UK the average short-term (12 weeks) management costs were about £8000 per patient, with hospitalisation accounting for nearly three quarters of this amount. Long-term costs were estimated at about £40,000, making the lifetime costs of managing a stroke patient almost £50,000 (Caro & Huybrechts, 1999).

1.2 Emotional consequences of stroke

Stroke can leave people with a wide range of difficulties including physical disability, cognitive impairment and communication problems. In addition to the physical effects of stroke there are behavioural, emotional and psychological consequences. The experience of a stroke, hospitalisation, or facing up to living with disabilities can affect emotional health (Stroke Association, 2001), and this can have important implications for stroke outcome. Emotional or affective responses which have been reported following stroke include:

- Depression (Åström, Adolfsson, & Asplund, 1993; Burvill, Johnson, Jamrozik, Anderson, Sterwart-Wynne et al, 1995; Herrmann, Black, Lawrence, Szekely, & Szalai, 1998; House et al, 1991; Robinson, Starr, & Price, 1984).
- Anxiety disorders (Åström, 1996; Burvill, Johnson, Jamrozik, Anderson, Stewart-Wynne et al, 1995; Gillespie, 1997).
- Apathy – absence or lack of feeling, emotion or interest in what is going on around you (Robinson, 1997).
- Emotional lability – sudden, easily provoked episodes of crying or laughing (House, 1987b; Robinson, 1997).
- Catastrophic reaction – short-lasting emotional outburst in response to a demanding task (Carota, Rossetti, Karapanayiotides, & Bogousslavsky, 2001).
- Mood and behavioural disturbances such as denial, irritability, disinhibition, aggressiveness, frustration and anger.

The study of emotional distress after stroke is important as it affects the ever-increasing number of stroke survivors and it can be an obstacle to rehabilitation. Distress can be detrimental to recovery through fatigue, lack of hope, and reduced participation in rehabilitation (Schubert, Taylor, Lee, Mentari, & Tamaklo, 1992). Distress after stroke has been associated with a number of negative outcomes including:

- Poorer functional/rehabilitation rehabilitation outcome (Herrmann et al, 1998; Kotila, Numminen, Waltimo, & Kaste, 1999; Parikh et al, 1990; Pohjasvaara, Vataja, Leppävuori, Kaste, & Erkinjuntti, 2001).
- Longer hospital stay (Cushman, 1988).
- Poor cognitive function (Andersen, Vestergaard, JØ, & Ingeman-Nielsen, 1996; Robinson, Bolla-Wilson, Lipsey, & Price, 1986).
- Lower quality of life (Jaracz, Jaracz, Kozubski, & Rybakowski, 2002).
- Suicidal thoughts and plans (Stenager, Madsen, Stenager, & Boldsen, 1998).
- Mortality (House, Knapp, Bamford, & Vail, 2001; Morris, Robinson, Andrzejewski, Samuels, & Price, 1993).

The National Service Framework for Older People (DOH, 2001) identified the importance of considering patients' emotional needs in stroke rehabilitation:

"Rehabilitation will vary according to needs but might include...clinical psychology for patients with problems affecting intellectual function or mood." (p.67)

"Long-term support should include...providing social and emotional support to minimise the loss of independence following the stroke, and help manage the consequences of stroke." (p.68)

"Service models: Staff training should include...the emotional needs of stroke patients"... (p.72)

Also, The National Clinical Guidelines for Stroke (RCP, 2004) stated that:

"Patients should be given information, advice and the opportunity to talk about the impact of illness upon their lives" (p.53)

"Patients should be screened for depression and anxiety within the first months of stroke, and their mood kept under review..." (p.53)

"Mood disorder that is causing persistent distress or worsening disability should be managed by or with advice from an experienced clinical psychologist or psychiatrist." (p.54)

1.3 Depression, anxiety and emotional distress

This thesis was concerned with emotional distress after stroke. The two emotional disorders that have received the most attention in stroke patients are depression and anxiety. This section will outline the constructs of depression, anxiety and the overlap between these and will argue for the study of emotional distress as a continuum rather than diagnostic categories.

1.3.1 Depression

Depression is the most commonly presented psychiatric disorder (Champion, 2000), and is referred to as the 'common cold' of psychopathology (Seligman, 1975). The central symptom is depressed mood, and this is more persistent than general feelings of sadness. Further symptoms include: loss of interest in activities, apathy, pessimistic thoughts, feelings of worthlessness, feelings of guilt, and suicidal thoughts. Depression can impact upon biological functioning, with symptoms including sleep disturbances, appetite changes, lack of energy, and loss of libido.

Symptoms of depression can be measured on a continuum using assessment scales and criteria exist to provide a categorical clinical diagnosis. The two current classifications for depression are DSM-IV (APA, 1994) and ICD-10 (WHO, 1992). Depressed mood and a loss of interest are the essential features of depression. For both DSM-IV and ICD-10 there are a minimum number of typical and associated symptoms required for depression diagnosis, and the minimum symptom duration is two weeks. The presence of depressive symptoms alone is not sufficient for diagnosis, there also needs to be evidence of sustained mood disturbance causing clinically significant distress in social, occupational or other key areas of functioning (Clark, Beck, & Atford, 1999).

Depression is considered to be the most common neuropsychiatric consequence of stroke (Robinson, 1997). There is widespread agreement that the early recognition and management of depression after stroke is desirable (Turner-Stokes & Hassan, 2002), yet depression is largely undiagnosed and most patients do not receive treatment for their depressive disorders (Wade, Leigh-Smith, & Hewer, 1987). Despite the fact that depression is a common and serious complication of stroke, it received little research attention until the last 20-30 years due to a long-standing attitude that depression is an understandable and expected psychological reaction to serious illness (Gustafson, Nilsson, Mattsson, Åström, & Bucht, 1995).

It has been found that within patients who do not meet diagnostic criteria for major depression, many show symptoms of depression (Eastwood, Rifat, Nobbs, & Ruderman, 1989; House et al, 1991; Morris, Robinson, & Raphael, 1990). It has been proposed that in stroke patients major depression should be distinguished from minor depression, a less severe form of depression (Robinson, 1998). Minor depression has been reported to account for 40%-60% of all post-stroke depression cases (Eastwood et al, 1989). Early studies used symptom criteria from DSM-III or DSM-III-R dysthymic disorder (symptoms must be present for at least two weeks) (Robinson, Kubos, Starr, Rao, & Price, 1984; Robinson, Starr, Kubos, & Price, 1983), but this is problematic as the nature and severity of symptoms are poorly defined (Morris, Shields, Hopwood, Robinson, & Raphael, 1994). DSM-IV has introduced 'minor depression' as research criteria, in which there are depressive symptoms but with subsyndromal presentation (APA, 1994).

Robinson et al (Robinson, Bolduc, & Price, 1987; Robinson, Starr, & Price, 1984) found that about one-quarter of patients with minor depression at three months post-stroke went on to develop major depression. Similarly, Burvill et al (1995) found that minor depression was persistent or developed into major depression and so there is evidence that minor depression captures an important group of stroke patients (Paradiso & Robinson, 1999). Studies have reported that depression scores were continuously rather than bimodally distributed after stroke and do not support a categorical distinction between 'major depression', 'minor depression' and 'not depressed' (Gainotti, Azzoni, Razzano, Lanzillotta, & Marra, 1997; House, 1988a). House et al (1991) challenged the subclassification of depression and argued that diagnosable caseness is a function of symptom severity rather than specific content. There is insufficient evidence for the use of minor depression as a distinct construct. However, findings from the studies considered here suggest that it would be more relevant to assess severity of distress rather than using diagnostic categories.

1.3.2 Anxiety

Anxiety is a normal response to a stressful situation, but this anxiety becomes a disorder when it is excessive and persistent and impacts upon everyday life. Symptoms of anxiety can be physical, such as shortness of breath, rapid heartbeat or palpitations, tightness in the chest and dizziness. Psychological symptoms include irritability, sleep disturbance and irritability. Diagnostic categories of anxiety include generalised anxiety disorder (GAD), panic disorder, obsessive compulsive disorders and phobic disorders. GAD is excessive and persistent anxiety and worry about several events or activities, accompanied by physical and psychological symptoms. A DSM-IV diagnosis of GAD requires symptoms to be present for at least six months and to have an adverse effect on the person's life. Symptoms of GAD include

restlessness, irritability, concentration difficulties, sleep disturbance and being easily fatigued. Panic disorder or panic attack refers to an abrupt episode of intense fear or discomfort. Obsessive compulsive disorders are uncontrollable, recurring obsessions (recurring thoughts, images or impulses) or compulsions (repetitive thoughts or actions that people feel they must do). Phobic disorders refer to excessive fear or anxiety of a situation or object that is disproportional to the realist danger.

Anxiety disorders found in stroke patients have included generalised anxiety disorder, agoraphobia and phobic disorder (House et al, 1991). A threatening event such as a stroke is likely to be associated with anxious states (Johnson, 1991). Panic disorders and obsessive compulsive disorder are quite rare following focal brain injury and so have not been widely studied in stroke (Robinson, 1998). Symptoms of anxiety reported in stroke include worry about changes in functional ability, avoiding friends because of fear of how they will react, and fear of a recurrent stroke being brought on by physical activity (House et al, 1991). The difficulty with symptoms of anxiety is whether these are specific to anxiety in stroke, as physical symptoms such as fatigue, sleep disturbance and concentration difficulties may result from the stroke itself. However, Robinson (1998) found that DSM-IV symptoms of anxiety more common in stroke patients with GAD than those who did not have anxiety. Like depression, anxiety can have adverse effects on daily functioning, interpersonal relationships and quality of life after stroke (Åström, 1996).

1.3.3 Emotional Distress

Historically no clear distinction was made between anxiety and depression. Kraeplin differentiated between *angst* (anxiety with melancholia) and *angestlichkeit* (characterised by helplessness), but Freud was the first to address anxiety and

depression as separate entities (Levine, Cole, Chengappa, & Gershon, 2001). There is a high comorbidity of anxiety and depression in the elderly; between one quarter and one half of depressed elderly were found to have comorbid anxiety disorders (Beekman et al, 2000; Lenze et al, 2001). Comorbid anxiety and depression has also been found in stroke (Åström, 1996; Burvill, Johnson, Jamrozik, Anderson, Stewart-Wynne et al, 1995) and scores on anxiety and depression scales were highly correlated (Gillespie, 1997; Townend, 2004). This suggests that it is difficult to study anxiety or depression separately in stroke. There is considerable symptom overlap between anxiety and depressive disorders, for example, four out of six symptoms of GAD in DSM-IV overlap with those of major depression (sleep disturbance, restlessness, concentration difficulty and fatigue). In the International Classification of Diseases depression supersedes anxiety in that if there is both anxiety and depression then this is classified as a depressive disorder (Bramley et al, 1988). Stein, Kirk, Prabhu, Grott and Terepa (1995) proposed a hypothetical diagnostic category of mixed anxiety-depression (MAD) for patients who present with subsyndromal anxiety and depression and MAD was found to be associated with disability comparable to anxiety or depression (for example, impact on family and home life). It has also been suggested that major post-stroke psychiatric disorder may actually be mixed anxiety-depression and that there is an overemphasis on post-stroke depression in the literature at the expense of considering other distress (Johnson, 1991). Also, House (1996) argued that the use of the term 'post-stroke depression' as a quasi-diagnostic category encourages the belief that depression associated with stroke is a specific syndrome when evidence does not support this. Anxiety disorders in stroke have not been widely studied compared with depression.

This may be because diagnostic systems give priority to major depression over anxiety in the diagnostic hierarchy.

The evidence considered here supported the study of distress after stroke as a continuum that is, symptom severity, rather than using diagnostic categories of anxiety and depression. Focusing on a diagnosis of major depression overlooked patients with high levels of distress but who did not meet criteria for a clinical diagnosis. The assessment of distress allows the study of symptoms of anxiety and depression that do not meet criteria for a clinical diagnosis. This approach was also advocated by Townend (2004). High comorbidity of anxiety and depression symptoms and disorder was found both in elderly and stroke populations. Therefore, the focus of this thesis was emotional distress, which refers to symptoms of anxiety and depression. As alluded to stroke studies have predominantly been concerned with depression rather than anxiety, therefore many of the studies in the subsequent literature review reflect this bias.

The aetiopathology of distress following stroke is a contentious issue in the literature. There are essentially two opposing views (Whyte & Mulsant, 2002): the first is that distress is caused by biological mechanism whereby the ischaemic damage directly influences neural circuits concerned with mood regulation (Robinson, Kubos et al, 1984), the alternative school of thought considers psychosocial mechanisms involving the social and psychological stressors related to stroke to be important (Gainotti, Azzoni, & Marra, 1999). The exact nature of psychological and social factors that predispose an individual to becoming distressed following stroke is a relatively neglected area of study (House, 1987a). Whyte and Mulsant (2002)

suggested that the causes of distress after stroke are likely to be multifactorial and the polarity of opinions obstructs a more comprehensive study of distress. They argued that a more systematic approach is required in which the relative contribution of each risk factor is investigated.

The focus of this thesis was the development of a theoretical framework to explore the factors relating to distress following stroke. The literature will firstly be reviewed to describe existing models of primary depression, that is, depression that does not occur in the context of a physical illness. The extent to which these models can be applied to stroke will be discussed. Secondly, the literature will be reviewed to consider the factors in the literature that have been reported to be associated with distress after stroke. This information will be synthesised to develop a theoretical framework to study factors associated with distress after stroke. Distress after stroke is an important area of study as it is associated with negative outcomes. Furthering our understanding of what factors are associated with distress after stroke will aid the identification of patients at risk of becoming distressed and will inform the development of therapies to treat distress following stroke.

1.4 Models of distress

This section will outline the major existing psychological and biological models of distress and evaluate evidence for these in stroke, in order to establish whether concepts from the psychological literature of primary depression are applicable to stroke. This is important to consider as treatments for distress have been developed from these theories. If the theories apply to stroke, then this may inform the development of effective interventions for distress. The psychological models that have been proposed refer to 'depression'.

1.4.1 Cognitive model of depression

The cognitive model conceptualises depression as a thought disorder. The most influential cognitive model is that of Beck (1976). A negative biasing of information processing and maladaptive thinking and perception are the fundamental features of depression (Beck, 1987). The thought content of depression centres on a significant loss; the individual perceives they have lost something essential to their happiness, such as an attribute or achievement. It can be argued that this parallels stroke, for example losses in independence, hobbies and social role (Noble, 1993). The cognitive theory in stroke concerns depressogenic beliefs and inaccurate assumptions developed about physical and cognitive losses, and life following stroke (Grober, Hibbard, Gordon, Stein, & Freeman, 1993).

The model proposed that we form assumptions or *schemas* (stable mental structures) based on early experiences, which are used to organise perceptions of the world and evaluate behaviour (Fennell, 1996). These schemas can be a diathesis for depression if they are dysfunctional and maladaptive (for example: *"In order to be a worthwhile person I have to be successful in everything I do"*). A critical incident or stressor,

such as that which resembles the earlier event, can activate dysfunctional schemas and generate negative interpretations of experiences so the individual takes in only (negative) information consistent with the schema and overlooks positive information (Hammen, 1997). For example a stroke patient may only see what they are unable to achieve. This results in *negative automatic thoughts*, so called as they are associated with unpleasant emotions and occur without conscious reasoning, and symptoms of depression. These thoughts concern personal loss and failure and there is a decrement in positive thinking. Depression can result in more frequent and intense negative automatic thoughts and a vicious cycle develops. Depressive symptoms fall into five areas: cognitive (e.g. poor concentration, difficulty making decisions); behavioural (e.g. withdrawal); motivational (e.g. loss of interest); affective (e.g. guilt) and somatic (e.g. sleep and appetite changes).

Negative automatic thoughts are characterised by the *cognitive triad*; negative thoughts about the self, the world and the future. The negative cognitive triad of a stroke patient may include: the self is seen as disabled – *"My body is ruined"*; a reduced ability to interact with or contribute to the world – *"Everything I do is terrible now"*; future is seen in terms of chronic disability – *"My arm will never do anything I want it to anymore"* (Grober et al, 1993; Noble, 1993). The negative cognitive set may be sustained across situations, such that during a positive experience the individual selectively attends to negative signs and draws inaccurate conclusions (Beck, 1987). Examples of cognitive distortions in stroke patients include: an all-or-nothing view of deficits *"Because I had a stroke I am totally ruined"*; disqualifying the positive and focusing on the negative *"The rehabilitation staff are telling me I'm doing well, but it's their job to say that"*; and distorted

emotional reasoning about the future *"I feel so hopeless about the future, I just know things won't get better"* (Grober et al, 1993).

Beck (1987) did not assert that cognitions cause depression. There is evidence that depression-related cognitions develop concomitantly with depression (Crandell & Chambless, 1986; Lewinsohn, Steinmetz, Larson, & Franklin, 1981). Clark, Steer, Beck and Snow (1996) found a linear association between the frequency of negative cognitions and depression severity. The relationship between negative cognitions and depression was strongest for depressed psychiatric inpatients when depression was measured on the Hamilton Rating Scale for Depression (an observer-rated measure), while for chronic medically ill hospitalised patients the relationship was strongest when depression was measured on the Hospital Anxiety and Depression Scale (HADS; a self-report measure of anxiety and depression designed for the physically ill). The HADS may have been more appropriate for the medical sample as it excludes somatic items. The degree of positive thinking may also be important, not just from a theoretical interest but because of implications for therapy, however few studies have addressed this (Ingram & Wisnicki, 1988).

The cognitive model would predict that depressed individuals have more negative thoughts about the self, the world and the future than those not depressed *(negativity hypothesis)* and that depression is characterised by a decrement or exclusion of positive self-referent thinking *(exclusivity hypothesis)* (Clark et al, 1999; Haaga, Dyck, & Ernst, 1991). In order for the cognitive model of depression to be supported in stroke, there should be evidence that depressed patients experience more negative cognitions and few positive cognitions than those not depressed. However, the

cognitions of medical patients have not been widely studied. Clark, Cook and Snow (1998) found that depressed medical patients reported significantly less negative cognitions (Beck Hopelessness Scale and Cognitions Checklist) compared with psychiatric inpatients. Negative cognitions and subjective symptoms distinguished major depression in the psychiatric sample while somatic and behavioural symptoms were the best discriminators in the medical sample. The findings were not sufficient to suggest that depression in the medically ill is disparate to depression in psychiatric patients, as the differences between the groups were quantitative rather than qualitative. However, it implies that further investigation of the cognitions of stroke patients is required to evaluate the applicability of the cognitive theory of depression to this population. Noble (1993) explored the cognitions of a small sample of community stroke patients (using Automatic Thoughts Questionnaire and Cognitive Style Test). The results indicated that depressed stroke patients showed a non-significant trend towards a negative cognitive style and reported more negative automatic thoughts than the non-depressed group. However, the study was limited as not all of the 44 patients completed all questionnaires, precluding detailed analysis. Noble (1993) also noted that patients found the scales long and taxing to complete, and some items were not applicable.

Cognitive-behaviour therapy (CBT) has been conducted with stroke patients to identify and challenge negative thinking and develop more accurate and positive thoughts. A pilot study found some evidence that CBT was effective in treating depression after stroke (Lincoln, Flannaghan, Sutcliffe, & Rother, 1997). Four patients showed consistent benefits, six showed some benefit and nine no benefit. However, a subsequent randomised controlled trial found CBT to be no more

effective than an attention placebo (Lincoln & Flannaghan, 2003). The applicability of the cognitive model of depression to stroke has therefore been questioned, as it is possible that CBT was not effective as the cognitive model may not be relevant in stroke. Existing studies of stroke (Noble, 1993) and medical patients (Clark et al, 1998) are limited by the assessments used. The cognitions measures were developed for psychiatric samples and may not have been an accurate test the cognitive model in the medically ill (Clark et al, 1998). Specialised measures of cognitions may be required for populations such as medically ill patients, as there may be specific issues (Clark et al, 1999). Therefore, it is possible that depressed stroke patients experience a preponderance of negative cognitions in comparison to positive cognitions, as would be predicted by the cognitive model of depression, but that these are stroke-related. However, the content validity of existing cognitions measures may be low in stroke patients and so not measuring relevant cognitions, and this may account for why previous studies have found limited evidence for the cognitive model in stroke.

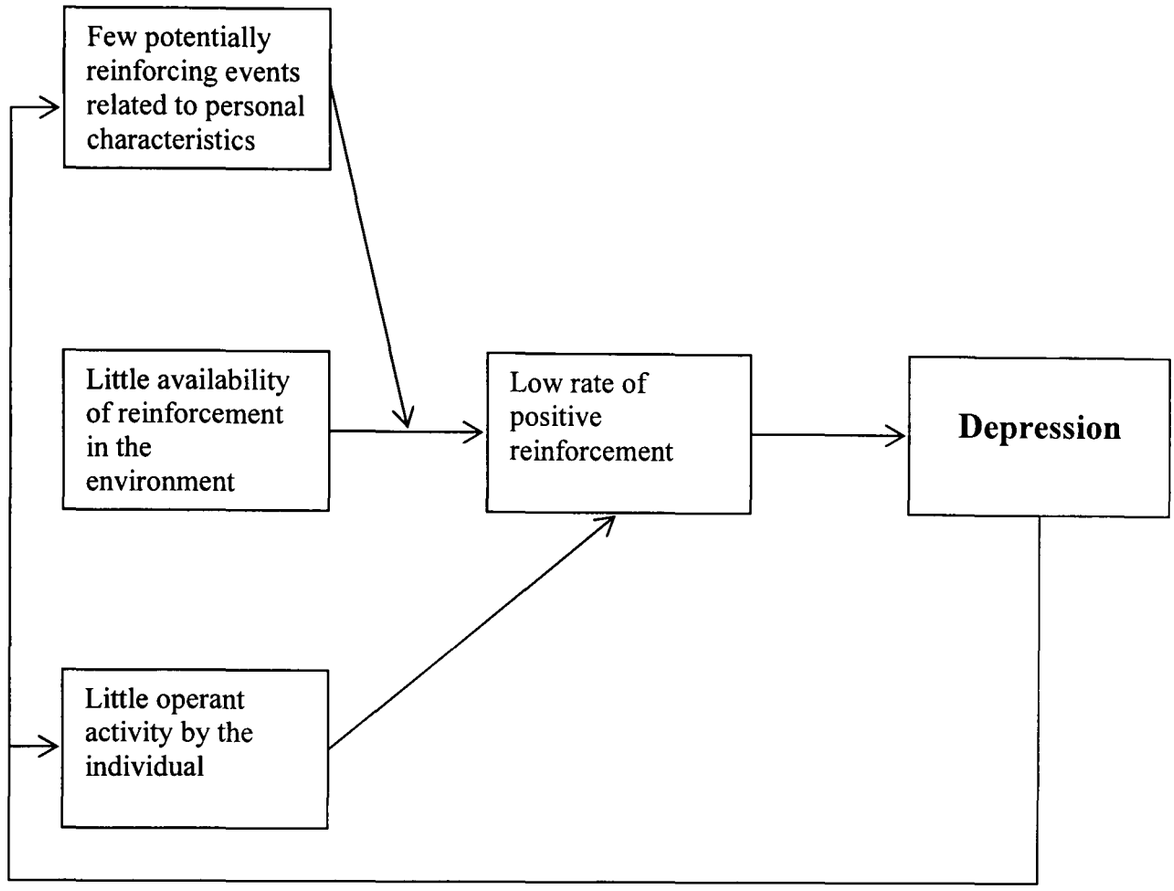
In response to this, Nicholl, Lincoln, Muncaster and Thomas (2002) developed the Stroke Cognitions Questionnaire (SCQ) to assess positive and negative cognitions of stroke patients. Items were developed from treatment notes of stroke patients who had received CBT for depression; therefore they are likely to be more relevant than scales developed for psychiatric samples, and should reflect cognitions related to stroke. Also, unlike most other scales, the SCQ also includes positive items. In a sample of hospitalised stroke patients, patients classified as depressed on the Beck Depression Inventory reported significantly more negative and significantly less positive cognitions than those who were not depressed. This provides some evidence for the cognitive model of depression in stroke and suggests that depression is

qualitatively similar in physical illness and in psychiatric patients as the same pattern of a dominance of negative cognitions was found (Nicholl et al, 2002). It also implies that studies should consider the appropriateness of the measures used to assess depression related cognitions in stroke or other medical populations, as items need to be relevant for the population. However, the SCQ was developed from a small sample of treatment notes and the researchers recommended some modifications to the scale. Nicholl et al (2002) have provided some evidence to suggest that the cognitive model of depression may apply to stroke but further validation work is required with the SCQ to confirm these findings.

1.4.2 Behavioural models of depression

Behavioural models propose depression arises from insufficient reward or positive reinforcement from the environment (Champion, 2000). Consequences of behaviour are important, and symptoms of depression are an overgeneralised response (e.g. loss of interest in activities) to a specific event (e.g. losing your job) (Gotlib & Hammen, 1992). Passive behaviours may be elicited to avoid punishment experienced following active behaviours. Lewinsohn (1974) proposed that central to depression is a lack of response-contingent positive social reinforcement, meaning that in social situations behaviour does not elicit reward. Low positive reinforcement can result from a deficiency in an individual's skills or behavioural repertoire, a dearth of potential reinforcers in the environment and decreased ability to enjoy pleasant events. These antecedents contribute to a low rate of positive reinforcement, little feelings of mastery, esteem and success, which in turn leads to depression. Initially depression may elicit sympathy from others, which reinforces the depressive behaviours, but over time this may become hostility and exacerbate depression. This model is summarised in Figure 1.2.

Figure 1.2 Behavioural model of depression



Within the behavioural approach, Seligman (1975) proposed the *learned helplessness* model of depression, central which is the individual's expectation of control over outcomes and reinforcement. If an individual comes to expect that aversive outcomes are likely or that desired outcomes are unlikely, then they will expect they can do nothing to influence the outcome. The individual will exhibit symptoms and behaviours characteristic of depression: motivational – reduced response initiation; cognitive – pessimistic expectation of future contingency; emotional – depressed mood (Twaddle & Scott, 1991). Abramson, Seligman and Teasdale (1978) expanded the model to include attributions, arguing that exposure to uncontrollable stimuli was not sufficient for depression; the individual must also expect future outcomes are uncontrollable. The model presented an attributional framework; depression is more

likely when a negative event is attributed to internal (the self), stable (recurrent factors) and global factors (affect a variety of situations).

Lewinsohn, Hoberman, Teri and Hautzinger (1985) proposed an integrative behavioural model of depression, suggesting that depression results from "...environmentally initiated changes in behaviour, affect and cognitions" (p. 344). The trigger event (the stressor) is an antecedent to depression if "scripted" (everyday) and important behaviour patterns are disrupted. Pleasant experiences and interactions which provided positive reinforcement are reduced. The trigger event and disruption of behaviour patterns result in negative emotional reactions and the degree of depression is related to the amount of detriment in positive reinforcement. Individuals act to reduce the aversive experience, and the ability to cope is influenced by environmental and dispositional factors. There is increased self-awareness if coping is unsuccessful, causing the individual to be self-critical and have negative expectancies. Behavioural withdrawal and dysphoria result from increased self-awareness and dissatisfaction, leading to behavioural, cognitive, emotional, somatic and interpersonal changes which are correlated with depression.

Evidence for the integrative model of depression was found in a cross-sectional study of MS patients in which fatigue and physical disability reduced the ability to be involved in recreations and hobbies, which in turn was related to depressed mood (Voss et al, 2002). This model has not been tested in stroke but it may contribute to a psychological framework to understand distress after stroke. A stroke can disrupt everyday behaviours and roles, such as participation in hobbies and social interactions which can reduce positive reinforcement. Increased self-awareness could

cause the patient to be self-critical if their recovery does not meet their expectations. These factors may lead to distress. Coping strategies and support from the social network may affect the impact of the stressor.

The behavioural approach can be applied to stroke. Stroke involves loss of function, independence and enjoyable activities. Central to these losses is helplessness and the ability to control valued aspects of daily life (Noble, 1993). In hospital patients forfeit control over daily life. They may also have to suspend enjoyable activities, such as visiting friends, watching television and gardening. These activities would be expected to provide feelings of esteem and mastery, through self-reinforcement and feedback from others. Whilst in hospital patients are dependent on others for basic needs, and when discharged they often still require assistance. Passive behaviours may therefore be exhibited. This fits with the sick role concept whereby patients become dependent on others (Segall, 1976). There are social norms for being 'sick' and adopting the 'sick role'. That is, patients are expected to be co-operative and may be passive. Taylor (1979) argued that the loss of control induced by hospitalisation is depersonalising. The hospital routine imposes restrictions; such as lights being switched off at certain times and these restrictions can evoke helplessness and reactance (including anger). Stroke patients have described feelings of dependency and powerlessness (Hafsteinsdóttir & Grypdonck, 1997). Laidlaw, Thompson, Dick-Siskin & Gallagher-Thompson (2003) described 'excess disability': the proportion of disability that is not a direct consequence of the physical or cognitive impairments, but is due to the experience of stroke. For example, an individual may withdraw from an activity as they are embarrassed about their hemiparetic arm. This is supported by the finding that the resumption of social

activities does not necessarily parallel physical independence (Feibel & Springer, 1982).

Low activity levels in hospital may contribute to low mood. There may be little opportunity for reinforcing events if the patient has minor control over activities and they perform little operant behaviour. Eight observational studies of patient behaviour on stroke units are summarised in Table 1.1. These showed activity levels were low in hospital and patients spent a majority of their day in passive behaviours, often solitary (i.e. sitting and doing nothing). Overall, therapeutic activities did not consume a large proportion of the day and most recreation time was spent on the ward. Patients may give themselves little self-reinforcement if they feel they are achieving little in rehabilitation. Only a minority of the patients in the study by Bernhardt, Dewey, Thrift and Donnan (2004) had moderate or severe strokes, indicating that patients with milder strokes also remain inactive in hospital. It is reasonable to suggest that helplessness may be induced by hospitalisation, which in combination with the lack of reinforcement due to low activity levels and contact with others, may contribute to distress. However, the observational studies did not examine the relationship between activity level and mood.

Behavioural approaches may also help explain distress after discharge. Patients are often unable to resume their pre-stroke lifestyle. Behaviours and activities that provided positive reinforcement may no longer be easy to perform, such as hobbies and social activities. Mayo et al (2002) assessed patients up to six months after stroke and found 65% reported restrictions in reintegration to normal living. The areas reported to be most problematic were travel, social and recreational activities,

and having an important activity to fill the day. Similarly, Astrom, Asplund and Astrom (1992) found leisure time and social activities were markedly reduced after stroke and were only partly resumed by one year. Feibel and Springer (1982) reported that in the first six months after stroke depressed patients (nurse's rating) had lost two-thirds of pre-stroke social activities compared with non-depressed patients who lost just under half. These studies illustrate that a large proportion of community residing stroke patients are living with the consequences of stroke and are at risk from reduced activity and social isolation, which may contribute to distress

Studies have also assessed leisure participation following stroke. Leisure has been defined as "activity chosen primarily for its own sake after practical necessities of life have been attended to" (Drummond, 1990, p.157). General psychological well-being is associated with contentment derived from leisure and social interaction (Sjögren, 1982). Leisure activities are expected to provide pleasure and positive reinforcement which enhances mastery and self-esteem, for example through contact with others. Sjögren (1982) found 75% of patients had a reduced frequency of leisure activities and this was associated with discontentment and stigmatisation. Many patients fail to resume activities that are purely for enjoyment, and this does not change with time (Parker, Gladman, & Drummond, 1997). Drummond (1990) found that 30 out of 37 leisure activities significantly decreased in patients assessed at about one year after stroke. The most popular leisure activities were watching television, visiting family/friends, reading newspapers, and listening to the radio. The two activities that increased were 'just sitting' and 'day dreaming'. These are passive behaviours not expected to elicit positive reinforcement. While it is intuitive that

leisure activity will decrease if patients are disabled, patients had varying levels of mobility and functional difficulties. Therefore, the decrease in leisure activities cannot be explained by disability alone.

Table 1.1 Observational studies of stroke patients in hospital

Study	Location	Sample	Summary of findings	Comments
Bernhardt et al (2004)	Australia	5 acute stroke units (<14 days after stroke)	- 53% of the time spent in bed; 27% sitting out of bed; 13% in therapeutic activities - Alone 60% of the time, 15% with family/friends - In or beside the bed for 89% of observations	- 6/58 patients had severe stroke - 9 patients restricted to bed
De Weerdt et al (2000)	Belgium (B) Switzerland (S)	Stroke units	B/S: 28%/45% of the day in therapeutic activities	- Most time spent in own room or therapy room
De Wit et al (2005)	Belgium, Germany, Switzerland, UK.	Stroke rehabilitation units	- Non therapy time 72%-89%, mostly spent sitting or lying in room - Most time spent interacting with no one (52%-65%)	- Activity patterns differed between centres
Keith (1980)	U.S.A.	Stroke unit (4 days – 7 years post-stroke)	- Solitary behaviour most frequent ~40% - Time spent in treatment: 21%-27% - Time spent in social interaction: 21%-24%	

Study	Location	Sample	Summary of findings	Comments
Keith and Cowell (1987)	U.S.A.	Stroke unit	- Treatment ~ 31% of the day, passive behaviour ~ 42% of the day - >half the time spent alone, ~1/3 spent with treaters, 4% with other people	
Lincoln, Gamlen and Thomason (1989)	Nottingham, UK	Stroke unit	2 observation times 45%-65% time in solitary activities; 35%-55% in interactive behaviour	- Most likely behaviour to occur was watching others
Lincoln et al (1996)	Nottingham, UK	Stroke unit (SU), general medical ward, healthcare of the elderly	SU patients spent less time by their beds and more time in rehabilitation and social areas than other two wards	- Proportion of time spent in therapeutic activity low across all wards
Tinson (1989)	Bristol, UK	Stroke unit (acute patients)	- 12% of the day spent in therapy - 39% of time spent in recreation (2/3 of this time spent watching others or looking out of the window)	- Nearly all recreation time spent on the ward

1.4.3 Biological theories of depression

The biomedical model assumes that disease can be accounted for by deviations from the norm of measurable biological variables (Engel, 1977). This is a reductionist approach and "mental" disease is conceptualised in terms of a disturbance of underlying physical mechanisms. The extent of the neuroanatomical substrates of depression is not fully understood. Two neurotransmitters implicated in depression are noradrenalin (NA) and serotonin (5-hydroxytryptamine; 5-HT). The catecholamine hypothesis proposed that depression was due to depletion of NA levels. Studies of cerebrospinal fluid (CSF) found lower levels of NA metabolites in depressed people (Nemeroff, 1998). NA circuits project to many areas, including the limbic system, which is know to play a role in regulating emotions. However, NA dysfunction has not been widely studied in stroke and there is no evidence for the NA hypothesis in stroke at present. It has also been suggested that depressed mood appears to be to some extent regulated by 5-HT levels (Staley, Malison, & Innis, 1998). It is known that 5-HT plays a key role in behaviours associated with depression, such as sleep and appetite. 5-HT pathways are widespread throughout the brain, with a majority of 5-HT neurones located in the dorsal and median raphe nuclei of the midbrain, with projections through the thalamus, hypothalamus, basal ganglia and widespread areas of the neocortex (Nobler, Mann, & Sackeim, 1999). Early evidence came from studies which found decreased levels of 5-hydroxyindoleacetic acid (5-HIAA; a metabolite of 5-HT) in the CSF of depressed people, and there is some evidence from post-mortem studies of an increased number of 5-HT receptors (indicating upregulation due to 5-HT depletion). For reviews see Nemeroff et al (1998) and Staley et al (1998).

It is therefore reasonable to hypothesise that disturbance in serotonergic circuits may be associated with depression in stroke patients. Reduced oxygen and blood flow in the lesioned area may lead to hypersecretion of cortisol and disruption in neurotransmitter systems (Hinkle, 1998). Ramasubbu, Flint, Awad and Kennedy (1998) reported serotonergic hypofunctioning in non-depressed stroke patients (n=8) compared to healthy controls (n=12), but sample sizes were small and highly selected. Studies have employed a neuroendocrine challenge paradigm to measure the response of the serotonergic system. Ramasubbu et al (1999) and Morris et al (2003) measured the response to d-fenfluramine (d-FEN), which increases release and inhibits reuptake of 5-HT, and this is assessed by measuring the release of prolactin (PRL). Ramasubbu et al (1999) found peak PRL responses were significantly greater in depressed stroke patients than non depressed stroke patients, but this difference was not significant when lesion laterality was taken into account, and nine of the 12 patients had right sided lesions. In contrast, Morris et al (2003) found PRL responses were blunted in stroke patients with major depression in the subacute period after stroke, and responses were unaffected by lesion laterality. Comparable results were reported by Sevinçock and Erol (2000). These studies suggest that stroke may have a detrimental effect on the serotonergic system in some patients, which may be related to depression. However, the neuroendocrine challenge presents methodological issues. Small sample sizes arise from rigorous exclusion criteria, for example excluding hypothalamic or pituitary infarcts, or patients without single hemisphere lesions. This also makes it difficult to match depressed and non depressed stroke patients on lesion and demographic characteristics. It is also possible that blunted PRL responses in stroke patients are mediated by non-serotonergic mechanisms such as timing after stroke.

Research is restricted as little is known about 5-HT synaptic markers in depression. In vivo studies are limited because of non-specific binding, and 5-HT may be sensitive to factors such as age and gender. Changes in major neurotransmitter systems occur with ageing (Nobler et al, 1999). There is currently little evidence in the living human brain to confirm the 5-HT hypothesis of depression in stroke. The development of in vivo brain imaging methods such as positron emission tomography (PET) and single photon emission tomography (SPECT) will enable the investigation of 5-HT synapses in the living brain of depressed individuals.

The second biological basis that has been considered is that regional cerebral blood flow (rCBF) is reduced in depressed individuals. Research is complicated in the elderly as reduced rCBF has been found in normal ageing, and co-existing dementia may be a confound (Nobler et al, 1999). Some studies have reported reduced rCBF in depressed patients compared with controls, while others have reported no difference (Lesser et al, 1994). Lesser et al (1994) found depressed individuals (not stroke) over 50 years had a global reduction in rCBF compared with controls. Yamaguchi and Kobayashi (1993) found that in a small sample of stroke patients depression severity was inversely correlated with rCBF in parieto-occipital regions of the right hemisphere and the anterior temporal region of the left hemisphere. At 14 months there was an inverse correlation between changes in depression scores and rCBF. However, this does not mean the reduction of rCBF was due to or specific to post-stroke depression (Yamaguchi & Kabayashi, 1993), as alterations in CBF in distant areas of the brain have been reported in depressed and non depressed patients following focal cerebrovascular lesions (diaschisis).

1.5 Diagnosis and assessment of distress in stroke patients

The National Clinical Guidelines for Stroke state "Patients should be screened for depression and anxiety within the first month of stroke, and their mood kept under review. In those patients who can respond to it, a standardised questionnaire may be used for screening, but any clinical diagnosis should be confirmed by clinical interview" (RCP, 2004 p.53-54). There are many diagnostic and screening measures for mood, consequently there is variation in assessments across studies which can make comparisons difficult. If there is heterogeneity in criteria and assessments across studies then researchers may not be referring to the same condition when they refer to 'depression', 'depressed mood' or 'distress'. Consequently, conclusions regarding the frequency and correlates of distress after stroke are not always based on an adequate account of what is meant by depression (House, 1987a). This section presents a summary of the issues concerning mood assessment in stroke. These issues should be considered when evaluating studies and informed the methodology used in this thesis.

Psychiatric interviews for DSM or ICD diagnoses, such as the Present State Examination (PSE), are considered as the gold standard. DSM-IV and ICD-10 have been used to diagnose depression and anxiety in stroke. This raises the question of whether such criteria can be validly applied to stroke, as these classifications were developed in younger, healthier people without neurological damage. Agreement between ICD-10 and DSM-IV to diagnose depression is poor in stroke; this may be because ICD-10 includes mild depression (Lincoln, Nicholl, Flannaghan, Leonard, & Van der Gucht, 2003). Robinson and Price (1982) and Robinson et al (1983) modified the PSE due to the somatic items, but the changes were not specified and

this makes comparison to other studies difficult. DSM-IV includes a category for 'mood disorder due to a general medical condition' in which the essential feature is "a prominent and persistent disturbance in mood judged to be due to the direct physiological effects of a general medical condition" (APA, 1994 p.366). Stroke is listed in DSM-IV as a condition 'directly' causing depression, although research does not necessarily support this (Whyte & Mulsant, 2002). No specific criteria are provided for this diagnosis and it is arguably difficult to decide whether depression is caused by stroke (Black, 1995). ICD-10 includes criteria for an organic depressive disorder. These newer diagnoses are not widely used in stroke.

The main advantage of DSM-IV or ICD-10 criteria is that they are considered to be the gold standard and are well recognised. However, diagnostic interviews have high specificity but lower sensitivity detecting depression, and this has also been found in stroke (Lincoln et al, 2003). The limitation with this method is that psychiatric interviews are time consuming and require training to conduct, and are therefore less widely used in hospital than self-report screening measures. Also, they provide a diagnostic category rather than assessing the severity of distress.

The diagnostic criteria of depression and anxiety are an all-or-nothing approach in that patients are classified as depressed/not depressed not anxious/not anxious. It is also useful to have a scale to provide a score of severity and monitor change (Turner-Stokes & Hassan, 2002), and patients identified as possible cases can be referred for a clinical interview. Such scales are of use when the researcher or clinician is interested in measuring the severity of distress rather than providing a clinical diagnosis. Self-report scales can require a patient to select from a group of statements

of graded severity or select a Likert-response, to indicate the presence or severity of thoughts, feelings or behaviours indicative of depression or anxiety. Cut-off scores exist so that patients who score above a determined threshold can be classified as probably 'depressed' and 'anxious'. However, a high score on a rating scale should not be equated with a psychiatric diagnosis (Whyte & Mulsant, 2002).

A variety of self-report scales have been used to assess distress in stroke, but most scales have not been validated in stroke (Aben, Verhey, Lousberg, Lodder, & Honig, 2002). There is low concordance between self-report measures and psychiatric interviews in stroke (Lincoln, Nicholl et al, 2003; Schramke, Stowe, Ratcliff, Goldstein, & Condray, 1998). In the Oxfordshire Community Stroke Project (a study of patients in the first year after stroke), scores on the Beck Depression Inventory (BDI) were not bimodal, indicating such scales measure symptom severity rather than cases (House, Dennis, Hawton, & Warlow, 1989; House et al, 1991). Self-report measures have high sensitivity (detecting all those that are cases), but low specificity (identifying non-cases as non-cases) in stroke (Lincoln et al, 2003). Some studies have found cut-off values need to be modified to increase the accuracy of classification in stroke (Johnson, Burvill, Anderson, Jamrozik, & Stewart-Wynne, 1995; Lincoln, Nicholl et al, 2003; O'Rourke, MacHale, Signorini, & Dennis, 1998), while others found existing values to be appropriate (Aben et al, 2002). Cut-off values can be set according to the purpose of measurement. It is recommended that sensitivity should be >80% and specificity >60% for diagnostic purposes, while sensitivity needs to be >90% so individuals with the problems are not missed (Lincoln et al, 2003). Self-report measures are brief and convenient, and have normative data, but are limited by their inflexibility and lower response rates (House,

1988b). However, some patients may have difficulty with such assessments as they rely on intact language skills, memory and attention.

Gordon and Hibbard (1997) advised that multiple sources of information are required to assess mood in stroke. This is particularly relevant for patients who are unable to participate in a clinical interview or complete self-report measures, such as those with aphasia. In addition to self-report it may also be useful to obtain information from a carer or relative. Early studies used global ratings of distress by an observer (Feibel & Springer, 1982), but these were not standardised or validated. More recently developed observational methods require the carer or relative to make ratings of apparent behaviour (e.g. sadness, crying) and vegetative symptoms (e.g. sleep and appetite disturbances) which are thought to reflect the presence of depressed mood. For example, the Signs of Depression Scale (SODS) (Watkins et al, 2001), Hospital Stroke Aphasic Depression Questionnaire (SADQ-H) (Lincoln, Sutcliffe, & Unsworth, 2000) and the Stroke Aphasic Depression Questionnaire Community version (Sutcliffe & Lincoln, 1998) were designed to measure the presence (SODS) or frequency (SADQ) of observable mood symptoms. As discussed elsewhere in this review, some researchers have found observed behaviours to be associated with depression (Fedoroff, Starkstein, Parikh, Price, & Robinson, 1991; Lipsey, Spencer, Rabins, & Robinson, 1986; Paradiso, Ohkubo, & Robinson, 1997), while others disagree (Gainotti et al, 1997; Stein, Sliwinski, Gordon, & Hibbard, 1996). For valid reports the informant should have frequent contact with the patient (Carota & Bogousslavsky, 2003). House et al (1989) alleged that judgements by carers or nurses may not be reliable, with nurse's ratings reflecting sympathy rather than objective judgement. However, carers correctly identified patients with major

mood disorders. For aphasic patients who are unable to reliably complete interviews or self-report assessments, observer ratings may provide a valuable source of information about the patient.

1.5.1 Assessing distress in patients with aphasia

The fundamental process in the clinical evaluation of psychiatric illness such as depression is verbal communication. The only method to attain a measure of internal mood state is to ask the patient (Stern, 1999), but this is problematic in patients with language impairment (aphasia). Patients with nonfluent aphasia may not have adequate language production, and those with fluent aphasia may have difficulty understanding written or spoken questions, or discriminating among items in a checklist (Stern, 1997). Existing interviews and self-report measures will be difficult to complete with these individuals using standardised administration. Consequently, patients with more than mild communication deficits are usually excluded from studies. However, researchers fail to define the criteria by which they screened for communication impairment. The exclusion of aphasic patients is likely to underestimate the impact of distress after stroke. While observer ratings can provide useful information, it is also desirable that the assessment of depression in aphasic patients should include some direct measure of internal mood, for example, the Visual Analog Mood Scales (VAMS) (Stern, 1997). Visual analogue scales (picture-based scales) usually consist of a 100mm line with anchor words and simple pictures (e.g. depressed/not depressed, neutral/happy) and patients are required to mark along the line to indicate how they are feeling.

1.5.2 Somatic and nonsomatic symptoms of distress

A debated issue in assessing distress in stroke patients is whether depression in stroke is akin to primary depression, and whether somatic symptoms are accurate

indices. Diagnostic criteria and assessment scales include somatic symptoms that may be a consequence of the stroke lesion or a reaction to hospitalisation. Symptoms such as fatigue and decreased appetite can be observed in stroke patients without depression, and sleep and appetite patterns can be influenced by the hospital environment. It may be difficult to ascertain how much of a patient's total score on a distress measure is attributable to physical disease or emotional disturbance (House et al, 1991). Some self-report scales have been constructed with these issues in mind. For example, the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was developed to reduce the bias of somatic items that may confound screening in hospitalised medically ill patients. The question has been raised regarding whether depression is over-diagnosed in stroke due to diagnostic criteria being dominated by somatic symptoms (Gordon et al, 1991; Hibbard, Gordon, Stein, Grober, & Sliwinski, 1993). Several studies have addressed this.

Lipsey et al (1986) compared syndrome profiles of depressed stroke patients with patients hospitalised for functional depression (DSM-III major depression). Present State Examination (PSE) scores were significantly lower in the stroke patients while Hamilton Rating Scale for Depression (HRSD) scores were similar in the two groups. Syndrome profiles on the PSE were comparable for post-stroke and functional depression and the researchers concluded that post-stroke depression is a secondary affective disorder. However, the group with functional depression would be expected to have more severe symptoms as they were hospitalised for depression, while the stroke sample included both acute and rehabilitation patients. Fedoroff et al (1991) evaluated whether depression in stroke was over diagnosed due to somatic symptoms. Stroke patients were assessed on the HRSD and the PSE within two

weeks of hospital admission. Both somatic and psychological symptoms except early morning waking were more frequent in depressed patients. To see whether DSM-III criteria over-diagnosed depression, one extra autonomic symptom was required for a diagnosis of major depression; this changed the diagnosis from major depression to no depression in three out of 46 patients. The diagnosis changed from major depression to no depression in five patients when two autonomic symptoms were required. Therefore, DSM-III criteria did not over diagnose major depression, although patients were assessed early after stroke. These findings suggest that both autonomic and psychological symptoms are associated with depressed mood in stroke patients.

Lispey et al (1986) and Federoff et al (1991) argued that existing diagnostic criteria are adequate for stroke. These studies assessed only patients at a single time point and it is possible that the specificity of symptoms change over time. To address this, Paradiso et al (1997) assessed patients on five occasions in the first two years after stroke on the PSE and the HRSD. Comparable to Fedoroff et al (1991), depressed patients exhibited more vegetative and psychological symptoms than those without depression. DSM-IV criteria were modified to include only specific symptoms (i.e. symptoms which were significantly more frequent in depressed patients), but this did not substantially change depression diagnoses. This indicates that DSM-IV criteria are adequate for identifying depression in stroke patients. However, there was a high attrition rate from the original sample of patients; only about half were assessed at each time point.

Other researchers argued that existing depression criteria require modification. Stein et al (1996) assessed hospitalised patients on the HRSD and the BDI and found somatic items had lower specificity than nonsomatic items. Gainotti et al (1997) developed the Post-Stroke Depression Rating Scale (PSDRS) to evaluate problems specific to stroke. Patients who were between two weeks and six months after stroke were assessed on the PSDRS and the HRSD and compared to patients hospitalised with functional depression. Symptom profiles on the PSDRS showed that patients with functional major depression exhibited 'unmotivated' symptoms such as depressed mood, guilt feelings, and loss of enjoyment, while stroke patients with major depression presented with (psychologically) 'motivated' symptoms such as anxiety, catastrophic reactions and depression when disability is problematic. There was a continuum between major and minor depression in stroke patients. Gainotti et al (1997) argued that post-stroke depression is a psychological reaction to a dramatic event, and that functional major depression and major post-stroke are not comparable. However, this conclusion is largely based on symptom profiles on the PSDRS. The PSDRS was a newly developed scale designed specifically for stroke patients, it is therefore not surprising that that depressed stroke patients with major and minor depression were similar, and that those with functional depression presented different symptom profiles. Also, the individuals with functional depression (n=17) were hospitalised for their condition, suggesting their depression was severe, and the sample size was small.

House (1988b) argued that there is much pointless discussion of whether patients are really depressed if they fulfil depressive criteria, but are concurrently physically ill. He suggested that if the definition of depression is descriptive then anyone who has

the symptoms has the condition, regardless of whether depression in the physically ill has a different aetiology. The studies reviewed in this section demonstrate that there is insufficient evidence to abandon existing depression assessments for stroke. However, it indicates that when selecting an appropriate measure for stroke patients, the researcher or clinician should examine whether it has been validated in stroke populations, particularly if it assesses somatic symptoms.

1.6 Factors relating to distress after stroke

1.6.1 Prevalence of distress after stroke

The reported prevalence rates of distress after stroke vary widely; a review found estimates varied up to four-fold across studies (Whyte & Mulsant, 2002). Prevalence estimates are influenced by different assessment measures and diagnostic criteria, inclusion and exclusion criteria (those with previous stroke, aphasia, or pre-existing depression often excluded) and the timing of assessments. It is likely that the time after stroke is important as this corresponds to different stages of recovery. This section will review the literature on the prevalence of distress after stroke as assessed using self-report measures or diagnostic interview. This will be informative for identifying whether time after stroke is related to distress. The studies are summarised in Table 1.2 and Table 1.3, these also show the inclusion criteria and assessments. These studies have primarily been concerned with depression.

Not all stroke patients are admitted to hospital and some studies have assessed distress in samples which included patients not hospitalised due to their stroke. For example, Wade et al (1987) identified patients from G.P.s, nurses, therapists and patients admitted to hospital. Such community studies are summarised in Table 1.2. Within the first month post-stroke between 11% (Wade et al, 1987) and 32% (House et al, 1991) of patients met the cut-off for depression on self-report scales and the prevalence of major depression was 11% (House et al, 1991). Estimates of depression were higher using self-report measures compared to diagnostic interview, due to diagnostic interviews having higher specificity (Lincoln et al, 2003). At six months the prevalence of depression using self-report measures was similar to one month, and major depression found in 9% of patients (House et al, 1991). By one year post-stroke between 16% (House et al, 1991) and 18% (Wade et al, 1987) of

patients met the cut-off on self-reports scales, indicating a reduction in depression symptoms. Major depression ranged between 5% (House et al, 1991) and 22% (Burvill et al, 1995). The lower rates reported by House et al (1991) may be due to patients having suffered a first stroke and being mildly disabled. There seems to be a reduction in depression between six months and one year after stroke. Although Burvill et al (1995) reported a higher rate of major depression, at one year than House et al (1991) Burvill et al only reassessed patients at one year if they were depressed at four months which biased the follow up sample towards those with lower mood. It is important also to consider whether the same patients were depressed at each point, as many studies were cross sectional. Longitudinal studies of a cohort of patients are informative. Wade et al (1987) found 17% were depressed at all three assessments and 10% who were not depressed when first assessed were depressed at one year. Similarly, House et al (1991) reported that 40% were depressed on the Beck Depression Inventory (BDI) at some point during the year, but few were consistently depressed. These studies suggest some patients develop depression early after stroke but this resolves within the first year, while others develop depression after the acute stages. Sharpe et al (1990, 1994) found the prevalence of major depression was 8%, and 14% were depressed on the HADS three to five years post-stroke, indicating depression occurs in the long-term after stroke, but that it is less common than in the early stages.

The remaining studies recruited patients from hospital/rehabilitation units or outpatients. These studies are likely to include patients with more severe strokes and disability. These are summarised in Table 1.3. Within two weeks post-stroke up to one quarter of patients met the cut-off or diagnostic criteria for depression (Berg,

Palomäki, Lehtihalmes, Lönnqvist, & Kaste, 2003; Robinson et al, 1987; Robinson et al, 1983; Robinson, Starr, Lipsey, Rao, & Price, 1984), with minor depression affecting up to one fifth of patients (Ng, Chan, & Straughan, 1995; Parikh et al, 1990). Between two weeks and two months after stroke about one third of patients were depressed on self-report scales (Berg et al, 2003; Knapp & Hewison, 1998; Spencer, Tomkins, Schulz, & Rau, 1995). The rate of major depression was more varied between 14% (Morris et al, 1990) and 35% (van de Weg, Kuik, & Lankhorst, 1999), although patients were more disabled in the latter study. At three months between 22% (Herrmann et al, 1998) and 47% (Kotila, Numminen, Waltimo, & Kaste, 1998; Morris et al, 1990) met self-report scores for depression. This is a wide range but Kotila et al (1998) noted that most patients scored as mild or moderately depressed and few were severely depressed. Rates of major depression were more conservative between 9% (Kauhanen et al, 1999) and 31% (Åström et al, 1993). The low estimate by the former of these studies may be because only patients with a first stroke were included, and those with previous psychiatric illness were excluded. At six months between 20% (Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 2000) and 44% (Bush, 1999) were reported to be depressed on self-report measures, while the estimates of major depression between 14% and 52% (van de Weg et al, 1999). Self-report estimates of depression remained similar at one year (21%-47%), but major depression was lower (14%-16%).

Longitudinal studies are informative in showing changes in prevalence over time, however attrition in the sample should be taken into account. van de Weg et al (1999) found an increase in major depression from 35% at three to six weeks after stroke to 52% at six months. However the sample was biased towards including

those with more severe impairments as patients had to score <110 on the Functional Independence Measure. Robinson et al (1983), Robinson et al (1984), and Robinson et al (1987) followed-up patients for two years however, less than half were reassessed and not all patients were assessed at each time interval. The studies were criticised for including a sample of predominantly younger males of lower socioeconomic status, and the Hamilton Rating Scale for Depression was modified in an unspecified way (Andersen, Vestergaard, Riss, & Lauritzen, 1994). In a systematic study, Aström et al (1993) reported fluctuations in the prevalence of major depression: the peak was 31% at three months and the lowest was 16% at one year, and 60% of patients who were depressed within the first three months after stroke had recovered by three years. This suggests the peak occurrence of depression is about three months and prevalence decreases by one year.

Not all patients who develop depression become depressed in hospital. For example, in one study 21% developed depression after they were discharged (Kauhanen et al, 1999) and Andersen et al (1994) reported that 30% of patients not depressed at one month developed depression between two and four months after stroke. It is therefore important to follow up patients after discharge. Depression is less common long-term after stroke for example Berg et al (2003) found that only five patients (12%) scored as depressed for the first time between one year and 18 months after stroke.

This review has indicated that the prevalence of depression was higher in patients admitted to acute hospitals or rehabilitation units compared to community studies. This is likely to be because hospitals and rehabilitation units are biased towards those with more severe strokes and persistent disabilities (Johnson, 1991), and social

circumstances may influence whether a patient is admitted to hospital (House, 1987b). More patients were classified as depressed using self-report assessments compared with diagnostic criteria. Variation in inclusion criteria made studies difficult to compare. Longitudinal studies showed depression can remain chronic (Astrom et al, 1993; Berg et al, 2003; Wade et al, 1987). It is important to follow-up patients following discharge, as they may be vulnerable to depression when the impact of the stroke becomes conspicuous. The peak prevalence of depression is between three and six months after stroke (Whyte & Mulsant, 2002). Despite variability in prevalence estimates, overall studies suggested there was an increased risk of depression following stroke (Aben et al, 2001). Two community studies included control groups and found the prevalence of major depression to be greater than that of age- and gender-matched controls (Burvill et al, 1995; House et al, 1991). Similarly, two hospital studies found stroke patients were more depressed than controls (Andersen et al, 1994; Desmond et al, 2003).

Robinson (1998) assessed 301 acute stroke patients and found that the prevalence of generalized anxiety disorder (GAD) was 22%; 40% of patients had comorbid GAD and major depression while 10% had GAD without comorbid depression. Further, if minor depression was also included, major or minor depression was found in 75% of patients with GAD. This indicates that in a majority of cases anxiety was associated with major or minor depression. However, this study was conducted early after stroke. Burvill, Johnson, Jamrozik et al (1995) assessed patients up to one year after stroke and used a non hierarchical approach to diagnosis; 12% of men and 28% of women had some form of anxiety disorder. The authors did not report additional stroke characteristics such as disability level; therefore it is difficult to establish

whether these were related to mood. Aström (1996) found that 28% of patients recruited from a stroke unit had GAD. This prevalence did not significantly change in the first three years after stroke and comorbidity with depression was high. However, Astrom et al (1996) modified DSM-III-R criteria as some symptoms could not be separated from stroke-related illness (such as breathlessness, nausea and dizziness). A community study of patients in the first year post-stroke found low levels of generalized anxiety (1% at one month and six months) (House et al, 1991). The reasons for this may be that patient had suffered a first stroke and were recruited from GPs and so are likely to have had milder strokes. Robinson (1998) reviewed studies of anxiety after stroke and concluded that the mean prevalence of anxiety disorders was 14.4% (across initial and follow up data) and if patients with or without depression was included then the mean prevalence was 21%. Anxiety is therefore also common after stroke, but the prevalence is lower than depression. Anxiety has been less widely studied than depression after stroke, although there is evidence for high comorbidity between anxiety and depression in stroke patients. This suggests that the study of emotional distress should consider assessing both symptoms of anxiety and depression.

Table 1.2. Community studies of emotional distress following stroke

Researchers	Number of patients & sample origin	Inclusion/exclusion criteria	Time after stroke	Assessment method and prevalence
Beekman et al (1998)	n=173 Random sample from population register	Excluded: > 85 years	Not specified	CES-D ≥ 16 27%
Burvill et al (1995)	n=294 Perth Community Stroke Study	Included: First stroke Excluded if: Aphasia too severe for psychiatric assessment	4 months 1 year (n=69 reassessed if depressed at 4 months)	DSM-III (using PAS) Major depression: 15% Minor depression: 8% Major depression: 22% Minor depression: 19%
House et al (1991)	n=128 Oxford Community Stroke Study	Included: First stroke	1 month 6 months (n=122) 1 year (n=115) 1 month 6 months 1 year	DSM-III major depression (PSE) 11% 9% 5% BDI ≥10 32%, ≥13 20%, ≥17 8% ≥10 32%, ≥13 15%, ≥17 6% ≥10 16%, ≥13 8%, ≥17 1%

Researchers	Number of patients & sample origin	Inclusion/exclusion criteria	Time after stroke	Assessment method and prevalence
Sharpe et al (1990); Sharpe et al (1994)	n=60 Oxfordshire Community Stroke Project	Included: First stroke Single lesion on CT Excluded: SAH	3-5 years after stroke	DSM-III (SCID) Major depression: 8% Dysthymic disorder: 10% HADS >9 14%
Wade et al (1987)	n=379 Community study from stroke register	Excluded those who they were notified of late, aphasic or confused	3 weeks (n=379) 6 months (n=377) 12 months (n=348)	WDI: 11% probably depressed, 22% depressed 12% probably depressed, 20% depressed 13% probably depressed, 18% depressed
Wilkinson et al (1997)	n=106 Community stroke register	Included: patients < 75 years old	4-5 years	n=96 HADS 8-10 14% HADS ≥ 11 23%

Table 1.3 Hospital based studies of emotional distress following stroke

Researchers	Number of patients & sample origin	Inclusion/exclusion criteria	Time after stroke	Assessment method and prevalence
Andersen et al (1994)	n=285 Consecutive stroke admissions	Excluded: Degenerative neurological disease, dementia, aphasia	 4-6 weeks 7-17 weeks 18-30 weeks 31-52 weeks	HDRS $\geq$ 13 21% 15% 9% 5%
Astrom et al (1993)	n=80 Recruited on stroke unit	Excluded those who suffered a recurrent stroke	 4-5 days after admission 3 months (n=76) 1 year (n=70)	DSM-III Major Depression 25% 31% 16%
Berg et al (2003)	n=100 Hospital admissions	First stroke Excluded: > 70 years old, alcohol abuse, antidepressants, psychosis	 2 weeks 2 months 6 months 12 months 18 months	BDI $\geq$ 10 27% 29% 23% 24% 26%

Researchers	Number of patients & sample origin	Inclusion/exclusion criteria	Time after stroke	Assessment method and prevalence
Bjerg Bendsen et al (1997)	n=128 Rehabilitation hospital	Excluded: previous stroke, previous organic brain disorder, psychiatric illness, aphasia	Not specified	DSM-III-R (using HRSD) 16% major depression
Bush (1999)	n=111 From Stroke Data Bank Project		7-10 days 3 months 6 months 12 months	CES-D $\geq$ 16 12% 28% 44% 39%
Cassidy, O'Connor and Keane (2004)	n=50 Rehabilitation unit	Included: 18-65 years old, sensory/motor impairment, no pre-existing disability	3-12 months 2 months later	DSM-IV 20% major depression 4% major depression
Collin, Tinson and Lincoln (1987)	n=111 Community- based stroke patients identified from stroke	20 patients unable to complete questionnaires due to deafness, aphasia or	1-2 years	WDI >14 56%; >18 34% GHQ >5 50%; >10 32%

Researchers	Number of patients & sample origin	Inclusion/exclusion criteria	Time after stroke	Assessment method and prevalence
Dam, Pederson and Ahlgren (1989)	n=92 Inpatients or outpatients	Excluded: Serious aphasia or somatic or psychiatric illness	Median 35 days (8-1280 days)	RDC 30% Minor or probable major depression
Dennis et al (2000)	n=372 In-hospital and outpatient clinics	Excluded if poor prognosis, SAH or illness which would dominate care	6 months	GHQ-30 >4 60% HADS >8 20%
Desmond et al (2003)	n=421 Consecutive admissions	Included if: ≥ 60 years old, aphasia, severe comorbid illness, dementia	3 months	HRSD > 11 11%
Eastwood et al (1989)	n=87 Stroke rehabilitation unit	Excluded: Severe aphasia or cognitive deficit	Assessed soon after admission to unit	RDC (using SADS) 54% met RDC for major or minor affective disorder

Researchers	Number of patients & sample origin	Inclusion/exclusion criteria	Time after stroke	Assessment method and prevalence
Fedoroff et al (1991)	n=205 Hospitalised patients	Excluded: Low consciousness, moderate/severe comprehension deficit	Within 2 weeks of admission	DSM-III (using PSE) Major depression 22% Minor depression 20%
Fukunishi, Aoki & Hosaka (1997)	n=47 Patients receiving follow-up treatment ,living at home		Approximately 3 years post stroke	DSM-III-R (using SCID) Major depression: 26%, Adjustment disorder: 15% SDS $\geq$ 50 28%
Gillen, Tennen, McKee, Gernert-Dott and Affleck (2001)	n=243 Admissions to inpatient rehabilitation	Excluded: severe aphasia, severe sensory or cognitive deficit	~ 4 days after admission to rehabilitation (entered rehabilitation mean 10.21$\pm$9.33 days post-stroke)	GDS $\geq$ 15 13%
Greveson, Gray, French and James (1991)	n=82 Hospital admissions	Excluded: SAH	$\geq$ 3 years	WDI >18 28% (n=67)

Researchers	Number of patients & sample origin	Inclusion/exclusion criteria	Time after stroke	Assessment method and prevalence
Herrmann et al (1998)	n=436 Stroke centre	Excluded: Subarachnoid or vertebrobasilar stroke, global/severe aphasia	3 months (n=150) 1 year (n=133)	MADRS $\geq$ 7 27% SDS $\geq$ 50 22% MADRS $\geq$ 7 22% SDS $\geq$ 50 21%
Hosking, Marsh and Friedman (2000)	n=79 Recruited from hospital, assessed at place of residence	Included: $\geq$60 years old, no psychiatric history in last 10 years	3 months	GDS > 9 34% (mild depression) GDS > 19 5% (severe depression)
Kauhanen et al (1999)	n=106 Consecutive admissions to stroke unit	Included: first stroke Excluded: previous psychiatric illness, alcoholism	3 months 12 months	DSM-III-R 53% overall 44% minor 9% major 42% overall 26% minor 16% major

Researchers	Number of patients & sample origin	Inclusion/exclusion criteria	Time after stroke	Assessment method and prevalence
Kellerman et al (1999)	n=82 Admissions to stroke unit	Excluded: TIA, disturbance of consciousness, severe aphasia or dementia	7 days after admission	BDI (13 items) ≥10 20% ≥ 15 <5% DSM-IV 27% adjustment disorder with depressed mood
King, Shade-Zedlow, Carlson, Feldman & Philip (2002)	n=53 Consecutive admissions to rehabilitation unit	Included: First stroke or minimal residual disability; planned discharge home with a caregiver	Prior to discharge 6-10 weeks post discharge 1 year post discharge 2 years post discharge	CES-D ≥ 16 30% 26% 17% 23%
Knapp & Hewison (1998)	n=30 Consecutive hospital admissions	Included: named carer, living independently pre-	<1 month 1 month post discharge	HADS ≥ 8 33% 37%
Kotila et al (1998)	n=321 Stroke register of hospital admissions	Included: First stroke	3 months 1 year (n=311)	BDI ≥ 10 47% 47%

Researchers	Number of patients & sample origin	Inclusion/exclusion criteria	Time after stroke	Assessment method and prevalence
Morris et al (1990)	n=99 Hospital admissions		~ 2 months (n=19 at 21 weeks) 15 months-2 years (n=56)	DSM-III (using CIDI) Major depression 14% Minor depression 18% Major depression 7% Minor depression 5%
Ng et al (1995)	n=52 Rehabilitation centre (admitted if rehabilitation potential)		Within 1 week of admission (average 22 days)	DSM-III-R Overall: 56% Mild depression: 35% Moderate depression: 19% Severe depression: 0.01%
Paolucci et al (1999)	n=470 Rehabilitation hospital	Excluded: Previous stroke, SAH, aphasia, pre-stroke depression	Median ~ 38 days	HRSD $\geq$ 18 27%
Paradiso & Robinson (1998)	n=301 Hospital admissions	Excluded: moderate or severe comprehension deficits	~ 2 weeks post-stroke	DSM-IV (using PSE) Major depression: 17%

Researchers	Number of patients & sample origin	Inclusion/exclusion criteria	Time after stroke	Assessment method and prevalence
Parikh et al (1990)	n=63 Consecutive hospital admissions	Included: Impairment in ADL after stroke No significant comprehension deficit	2 weeks 2 years	DSM-III (PSE) Major depression: 19% Minor depression: 21% Major depression: 24% Minor depression: 6%
Pohjasvaara et al (2001)	n=390 Consecutive hospital admissions	Included: 55-85 years Excluded: aphasia, poor general condition	3 months (n=390) 15 months (n=276)	DSM-III-R (PSE) Major depression: 26% (n=256) Minor depression: 13% (n=256) BDI ≥10 44% BDI ≥ 10 45%
Robinson et al (1982)	n=103 Stroke clinic		< 6 months – 15 years	GHQ ≥ 5 29%

Researchers	Number of patients & sample origin	Inclusion/exclusion criteria	Time after stroke	Assessment method and prevalence
Robinson et al (1983, 1984, 1987)	n=103 Consecutive hospital admissions Majority receiving outpatient medical care	Excluded: Decreased consciousness, aphasia	< 2 weeks 3 months (n=40) 6 months (n=50) 1 year (n=37) 2 years (n=48)	DSM-III (using PSE) Major depression: 27% Dysthymic depression: 20% Major depression: 18% Dysthymic disorder: 28% Major depression: 34% Dysthymic depression: 26% Major depression: 14% Dysthymic depression: 19% Major depression: 21% Dysthymic depression: 21%

Researchers	Number of patients & sample origin	Inclusion/exclusion criteria	Time after stroke	Assessment method and prevalence
Sinyor et al (1986)	n=64 Rehabilitation hospital	Included: First stroke Excluded: Comorbid medical conditions, receptive aphasia, > 85 years old, antidepressants	'Within weeks' of stroke	SDS $\geq$ 60 moderate-severe depression 22% SDS 50-59 mild depression 25%
Spencer, Tompkins, Schulz and Rau (1995)	n=87 Recruited from hospital	Included: First stroke, no psychiatric history, no progressive medical condition, community prior to stroke Excluded: Severe aphasia	3-10 weeks post-stroke 6 months later	CES-D 28 (cut-off 23) 33% 25%

Researchers	Number of patients & sample origin	Inclusion/exclusion criteria	Time after stroke	Assessment method and prevalence
Starkstein et al (1989)	n=93 Acute hospital and rehabilitation admissions	Included: First stroke Single right hemisphere lesion	Before 60 days post-stroke	DSM-III (using PSE) 18% major depression 12% minor depression
van de Weg et al (1999)	n=85 Patients admitted for clinical inpatient rehabilitation	Included: FIM<110 Excluded: history of depression, prior stroke, comorbidity	 3-6 weeks 6 months	If GDS ≥ 8: then subjected to DSM-III-R criteria for major depression 35% 52%

Abbreviations: BDI=Beck Depression Inventory; CES-D = Centre for Epidemiological Studies-Depression Scale; CIDI=Composite International Diagnostic Interview; DSM = Diagnostic and Statistical Manual of Mental Disorders; FIM=Functional Independence Measure; GDS = Geriatric Depression Scale; GHQ = General Health Questionnaire; HADS = Hospital Anxiety and Depression Scale; HRSD =Hamilton Rating Scale for Depression; MADRS=Montgomery Asperg Depression Rating Scale; OCSP=Oxford Community Stroke Project; PAS = Psychiatric Assessment Schedule; PCSS = Perth Community Stroke Study; PSE = Present State Examination ; RDC = Research Diagnostic Criteria; RS=Rankin Scale; SADS = Schedule for Affective Disorders and Schizophrenia; SAH=Subarachnoid haemorrhage; SCAN=Schedules for Clinical Assessment in Neuropsychiatry; SCID=Structured Clinical Interview for DSM-III-R; SDS=Zung Self-Rating Depression Scale; WDI = Wakefield Depression Inventory

1.6.2 Age

It has been suggested that elderly people are predisposed to distress as a result of age-related structural and biochemical changes, physical diseases and psychological losses (Skoog, 1997). There is a consensus that distress is common in old age and a majority of studies have shown that the prevalence of distress increases for those over 65 years (Snowdon, 2001). Those who suffer a stroke at retirement age could be adversely affected by stroke, as plans for retirement may have to be forfeited (Collin et al, 1987). Conversely, it could be proposed that younger patients are more susceptible to distress. Stroke has a detrimental effect on body image and self-esteem of younger survivors (Keppel & Crowe, 2000). Neugarten (1996) suggested that individuals have a "social clock", a socially prescribed timetable for major life events, and so these are anticipated. For example, there are social norms for the age at which people expect to get married, have children and suffer illnesses. According to this view, older people will be better practiced at making psychological adaptations to life events, and an event such as chronic illness is more expected by older people (Neugarten, 1996). For these reasons it is relevant to examine whether age is related to distress after stroke.

Older age was found to be related to distress in five of the studies reviewed. This was found in the first two weeks (Robinson et al, 1982), three months (Kotila et al, 1998; Herrmann et al, 1998) and one year after stroke (Kauhanen et al, 1999). Berg et al (2003) found that older age was associated with depression at two months after stroke, but this was not significant after this point, although the sample were relatively young (mean age 55 years). Sharpe et al (1994) reported older age to be a risk factor for distress three to five years post-stroke, although this may be an artefact

of older patients being more likely to be institutionalised. One study found increasing age to be correlated with distress in females only (Burvill et al, 1995).

Three studies reported an association between younger age and severity of distress. This was found at two weeks (Paradiso & Robinson, 1998) and four months after stroke (Burvill et al, 1995), although in the latter study this was significant for men only. These studies only assessed patients early after stroke. Paolucci et al (1999) assessed patients one month after stroke and found that distress was lowest in those less than 45 years old or older than 85 years old. The association between younger age and distress seems to be apparent only in the acute stages after stroke.

The remaining studies reported no significant relationship between age and distress up to three years after stroke (Andersen et al, 1995; Astrom et al, 1993; Cassidy et al, 2004; Collin et al, 1987; Dam et al, 1989; Dennis et al, 2000; Eastwood et al, 1989; Gillen et al, 2001; Hosking et al, 2000; King et al, 2002; Morris et al, 1990; Parikh et al, 1990; Pohjasvaara et al, 1998; Robinson et al, 1982; 1984; Sinyor et al, 1986; Spencer et al, 1995; Starkstein et al, 1989; Wade et al, 1987). This finding is unlikely to be due to the ages of the samples as the youngest mean age was 51 years (Cassidy et al, 2004) and the oldest 74 years (Hosking et al, 2000). However, Collin et al (1987) noted that those who responded to participate in the postal survey in their study were significantly younger than those who did not respond. The recruitment method may affect the age of the sample as older people may not response to postal recruitment or may decline to participate.

Most studies found that age was not significantly related to distress. Disagreements in the literature may be partly due to differences in the timing and location of assessments (Berg et al, 2003). Age itself does not predispose or protect an individual from distress, but rather distress may be associated with age-related factors such as disability (Snowdon, 2001). In non-stroke elderly distress symptoms have been found to be more frequent among the oldest old, but this is largely accounted for by age-related characteristics including an increased proportion of women, physical disability, and lower socioeconomic status (Blazer, 2003). It is likely that age does not account for a large proportion of the variance in distress. Therefore age should be examined in the context of other related risk factors such as disability levels and social circumstances, such as social support and living alone.

1.6.3 Gender

It is documented in psychiatric epidemiology that there is a higher prevalence of depression in women compared to men, with the female/male risk ratio about 2:1 (Kessler, 2003), and this has also been reported in primary care settings (Maier et al, 1999). It is unclear whether this is attributable to biological or social factors (Bebbington et al, 1998). The National Survey of Psychiatric Morbidity (Great Britain) found the effect of gender was age-dependent: the preponderance of depression in women was only evident in those under 55 years old (Bebbington et al, 1998). In contrast, a European study found gender differences did not attenuate as age increased (Prince et al, 1999). If women are more vulnerable to distress this could lead one to predict that when faced with the same event, such as a stroke, that women would be more likely to become distressed than men (Paradiso & Robinson, 1998).

Ten studies reported distress to be more prevalent or more severe in women compared with men (Andersen, Vestergaard, Ingeman-Nielsen, & Lauritzen, 1995; Angeleri, Angeleri, Foschi, Giaquinto, & Nolfe, 1993; Herrmann et al, 1998; Kotila et al, 1998; Ng et al, 1995; Paolucci et al, 1999; Paradiso & Robinson, 1998; Wade et al, 1987). This relationship was reported between two weeks to up to five years after stroke, although Kotila et al (1998) found an effect for female gender at three months but not one year after stroke. Burvill et al (1995) found minor depression to be more prevalent in women than men. In contrast, two studies found male gender to be associated with distress. Berg et al (2003) found men were at a greater risk of being distressed at 18 months after stroke, although gender was not significant before this time. The younger age of the sample (mean age 55 years) might account for the findings. Similarly, Morris et al (1990) found men to be more likely than women to be distressed up to two years after stroke. Physical disability could be of greater importance to men, especially those of working age (Berg et al, 2003).

The remaining studies found gender to be unrelated to distress (Kauhanen et al, 1999; Pohjasvaara et al, 1998; Åström et al, 1993; Bjerg Bendsen et al, 1997; Cassidy et al, 2004; Colin et al, 1987; Dennis et al, 2000; Gillen et al, 2001; Greveson et al, 1991; Hosking et al, 2000; King et al, 2002; Parikh et al, 1990; Robinson et al, 1982;1984;1987; Spencer et al, 1995; Starkstein et al, 1989; Dam et al, 1989; Eastwood et al, 1989; Sinyor et al, 1986). This was found between two weeks and over three years post-stroke. Burvill et al (1997) reported that the age distribution differed according to gender. In males, those under 60 years old were more likely to be depressed, while more females who were in the older age groups had major depression.

The literature regarding gender-differences in distress is inconsistent and overall two-thirds of the studies found gender was unrelated to distress. This could indicate that gender is not significant factor, although in some studies there was a trend for females to be at greater risk. Andersen et al (1995) argued that an association between female gender and depression is probably a reflection of sociodemographic differences, as women generally have lower socio-economic status and often lower education than men (Nolen-Hoeksema, 1987). Patients with a history of severe depression were excluded from some studies; therefore more females are likely to have been excluded as they are reported to be more vulnerable to depression (Kessler, 2003). The relationship between gender and distress is likely to be influenced by factors such as social role, marital status and occupational status, which have been found to be significant in primary care settings (Maier et al, 1999).

1.6.4 Marital status and living arrangements

Marital status is reported to influence the rates of primary affective disturbances, with rates of depression higher in those divorced, widowed or separated, and marriage has been found to have more protective effects in men (Bebbington, 1987). A study of over 65 year olds across 14 European countries found that depression scores tended to be lower among the married and never married in comparison to the widowed, divorced or separated (Prince et al, 1999). In stroke patients marriage may have positive effects such as practical support and having someone to talk to. Conversely, marriage may also have a negative influence as the patient may feel they are a burden, they may be criticised by their spouse, or the marriage may not be happy. Marital status may affect emotional adjustment to stroke, but the direction of this is unclear. Further, the distress may be influenced by living circumstances, such

as whether a patient lives at home or in a nursing home (Hosking, Marsh, & Friedman, 1996).

Ten studies found no association between marital status and distress up to five years after stroke (Bjerg Bendsen et al, 1997; Eastwood et al, 1989; Greveson et al, 1991; Herrmann et al, 1998; Morris et al 1990; Paradiso & Robinson, 1998; Parikh et al, 1990; Robinson et al, 1982; Sharpe et al, 1994; Starkstein et al, 1989). Beekman et al (1998) found that those without a partner were more likely to be distressed after a stroke, although the time after stroke at which patients were assessed was unspecified. One study found divorce/separation to be related to an increased risk of depression four months after stroke (Burvill et al, 1997). There is therefore little evidence in the studies reviewed that marital status is related to distress after stroke. It is possible that the overall support network and the patient's satisfaction with this are more important than the presence of a spouse.

Living arrangements have been less widely considered. Five studies found a relationship between living arrangements and distress. Andersen et al (1995) reported that those living alone at one year after stroke were more likely to be distressed. In contrast, Aström et al (1993) found living alone to be a risk factor distress when patients were assessed in hospital but not when assessed up to three years after stroke. This is surprising as it would be expected that living alone would be more important when the patient had been discharged from hospital. Burvill et al (1995, 1997) reported that those in a nursing home at four months after stroke had an increased risk of depression, and similarly Sharpe et al (1994) found that those living in an institution three to five years after stroke were more likely to be depressed.

These findings may be secondary to the fact that those who suffer a more disabling stroke are more likely to be admitted to a nursing home. Wade et al (1987) reported a decrease in the risk of distress up to one year after stroke in women living alone, although this did not account for a large proportion of the variance in distress scores. Six studies found no relationship between living alone and distress up to 18 months after stroke (Berg et al, 2003; Bjerg Bendsen et al, 1997; Dennis et al, 2000; Desmond et al, 2003; Kotila et al, 1998; Pohjasvaara et al, 1998). There is some evidence that distress is greater in those transferred to institutional care, although this may be an artefact of suffering a more disabling stroke. However, living arrangements do not appear to be an important risk factor for distress and do not account for much of the variance in distress.

1.6.5 Socioeconomic status (SES)

Low socioeconomic status (SES) has been associated with high psychiatric morbidity, disability and poorer access to healthcare, although the relationship may be confounded by gender as women tend to have a lower SES (Lorant et al, 2003). This supports the notion that those with higher SES will possess better resources such as an internal locus of control, adaptive coping, better social support and higher self-esteem to buffer stress. Recent psychiatric epidemiological surveys have not found a consistent relationship between SES (indicators such as income and years of education) and depression in the general population (Lorant et al, 2003). It can be argued that those with a lower educational level have less economic and social resources to successfully cope with stressful events, alternatively, over time those with lower education may develop immunity to stressors. The relationship between SES and distress in stroke has not been widely studied.

One study found lower SES to be related to distress two weeks after stroke (Paradiso & Robinson, 1998), although SES was not a unique predictor. The remaining studies found SES to be unrelated to distress (Andersen et al, 1995; Bjerg Bendsen et al, 1997; Burvill et al, 1997; Dennis et al, 2000; Eastwood et al, 1989; King et al, 2002; Morris et al, 1990; Parikh et al, 1990; Pohjasvaara et al, 1998; Robinson et al, 1982; Sharpe et al, 1994; Spencer et al, 1995; Starkstein et al, 1989) up to five years post-stroke. In contrast, Paolucci et al (1999) found those with a high school degree had an increased risk for depression at about one month after stroke and proposed that those with a higher level of education may be more knowledgeable of the impact of stroke. However, Eastwood et al (1989) found education level to be unrelated to depression up to four months after stroke. The findings may be affected by the different ages and locations of the samples.

There is little consistent evidence that SES is related to distress after stroke, although it has not been widely studied. Indicators of SES have varied across studies. Robinson and colleagues (Parikh et al, 1990; Morris et al, 1990; Robinson et al, 1982; Starkstein et al, 1989) used the Hollingshead Index of social class which is based on educational level and occupation. Patients with lower SES were over-represented in Robinson's studies, for example in two studies over three-quarters of patients were Hollingshead classes IV or V (working class) (Parikh et al, 1990; Starkstein et al, 1989). Other studies used indicators such as education or occupation (Dennis et al, 2000; Eastwood et al, 1989; Pohjasvaara et al, 1998) or income (Spencer et al, 1995). It is likely that SES may have a differential effect according to healthcare systems. In the UK for example stroke patients have free healthcare such as hospitalisation, and equipment when discharged.

1.6.6 Previous stroke

Some researchers have addressed whether distress is greater in patients who have had a previous stroke. Such a relationship could be due to a greater understanding of the effects of stroke and the knowledge that each stroke increases the risk of a subsequent stroke (Hosking et al, 2000). It is also possible that those who have had more than one stroke are older and more disabled. It is difficult to determine whether patients who have had a second stroke are more distressed, as patients who have suffered a previous stroke were excluded from eight of the studies (Berg et al, 2003; Bjerg Bendsen et al, 1997; Kotila et al, 1998; Paolucci et al, 1999; Sharpe et al, 1994; Sinyor et al, 1986; Spencer et al, 1995; Starkstein et al, 1989), arguing that it is difficult to determine whether distress was a result of the most recent stroke. Those studies that included patients with a previous stroke have failed to record residual disability.

Four studies reported that distress was greater in those who have had a previous stroke (Andersen et al, 1995; Dennis et al, 2000; Eastwood et al, 1989; Hosking et al, 2000). However, Eastwood et al (1989) did not find a relationship when patients were assessed in hospital and the relationship reported at four months after stroke was only applicable to those with RH lesions. Seven studies found no relationship between having a previous stroke and distress (Beekman et al, 1998; Collin et al, 1987; Desmond et a, 2003; Morris et al, 1990, Parikh et al, 1990; Pohjasvaara et al, 1998; Robinson et al, 1982). King et al (2002) found no relationship when patients were assessed prior to discharge but at two years after stroke those who had suffered a previous stroke were *less* likely to be depressed than those who had suffered a first stroke, although 89% of the sample had suffered a first stroke.

There is limited evidence to support the hypothesis that those who have had a previous stroke are more distressed than those who suffered a first stroke. The review was limited by the fact that many studies exclude patients who have had a previous stroke. Nevertheless, the exclusion of patients who have suffered a previous stroke is likely to overlook some patients who are at risk of being distressed, and this may also lead to the exclusion of older patients who were disabled at the time of their stroke. It is therefore important not only to record whether a patient has had a previous stroke, but also whether patients had residual disability from this.

1.6.7 Personal history of depression and family psychiatric history

It is reasonable to assume that personal or family psychiatric history might influence the development or severity of distress following stroke (Morris, Robinson, Raphael, Samuels, & Molloy, 1992). Within non-stroke populations there is the 'scar hypothesis', the idea that remitted depression leaves psychological scars, such as negative cognitive patterns, which may leave an individual vulnerable to subsequent depression (Just, Abramson, & Alloy, 2001). However, there is little evidence to support this (Zeiss & Lewinsohn, 1988). It can also be argued that some individuals are susceptible to recurrent depression due to environmental or psychological factors (Zeiss & Lewinsohn, 1988). Personal psychiatric history has not been widely examined, and many studies excluded patients with a psychiatric history. The extent of psychiatric or depressive history is rarely documented. A review found that no two studies used similar methods to establish history of psychiatric disorder (Spencer, Tompkins, & Schulz, 1997), and not all studies report the methodology. Methods ranged from a comprehensive review of the patient's and a first-degree relative's life history (Morris et al, 1990) previous treatment for depression (Cassidy et al, 2004)

and reviewing clinical charts (Morris et al, 1990), making comparisons across studies difficult.

Eight studies found that having a personal history of depression was related to distress up to one year stroke (Andersen et al, 1995; Burvill et al, 1997; Eastwood et al, 1989; Gillen et al, 2001; Herrmann et al 1998; Ng et al, 1995; Paradiso & Robinson, 1998; Pohjasvaara et al, 1998). In two of the studies a personal history of depression was a significant risk factor in women only (Burvill et al, 1997; Paradiso & Robinson, 1998), therefore gender may be relevant. Nine studies found no support for a relationship up to three years after stroke (Astrom et al, 1993; Cassidy et al, 2004; Dam et al, 1989; Desmond et al, 2003; Morris et al, 1990; Robinson et al, 1982; Sharpe et al, 1994; Starkstein et al, 1989). Seven studies excluded patients with a history of depression (Berg et al, 2003; Bjerg Bendsen et al, 1997; Hosking et al, 2000; Kauhanen et al, 1999; Paolucci et al, 1999; Sinyor et al, 1986; Spencer et al, 1995). Inconsistent findings may be partly attributable to different procedures used to define and ascertain psychiatric history (Spencer et al, 1997). There is equivocal evidence that a personal history of depression is associated with distress following stroke. The argument for excluding patients with a history of depression is that it may be difficult to ascertain whether patients were depressed at the time of the stroke. However, this review indicates that excluding patients with a personal history of depression excludes patients who may become distressed following stroke, although a history of depression did not account for a large proportion of the variance in distress. Researchers who include patients with a history of depression should report the criteria used to determine this.

Family psychiatric history has not been widely studied. Two studies reported an association between a family history of affective disturbance and distress up to two months (Morris et al, 1990) and two years (Starkstein et al, 1989) after stroke. Three studies found no relationship up to five years post-stroke (Andersen et al, 1995; Dam et al, 1989; Sharpe et al, 1994). Varying criteria were used to define family psychiatric history. For example, Andersen et al (1995) defined positive family psychiatric history if there was mental disorder in a first degree relative. At present there are few studies on this relationship and it is difficult and often impractical to obtain an accurate psychiatric history from family members.

1.6.8 Lesion location

There is currently no known neuropathology found to be consistently associated with primary or secondary mood disorders (Robinson, 1998). In the 1980s a series of seminal studies were published that proposed an association between the interhemispheric and intrahemispheric location of the lesion and depression after stroke (Robinson, Kubos et al, 1984; Robinson, Starr, Lipsey et al, 1984). It was reported that that depression severity was significantly correlated with proximity of the lesion to the frontal pole in patients with left hemisphere lesions (Robinson et al, 1984; Robinson & Szetela, 1981). The researchers suggested this may be due to disruption of neurotransmitter pathways running from the frontal pole to posterior cortical regions. Subsequent studies have presented mixed findings and the lesion location argument remains controversial. Findings may be complicated by interactions with factors such as disability level, previous stroke and psychiatric history (Eastwood et al, 1989). The study of a relationship between lesion location and distress after stroke is of interest as it would aid the early identification of patients at risk of becoming distressed and the development of interventions. This

relationship has been studied with respect to three lesion characteristics: hemispheric side of lesion (left hemisphere versus right hemisphere); intrahemispheric location of lesion (anterior versus posterior and distance of the lesion from the frontal pole) and lesion volume. This review will consider the findings regarding these.

Hemispheric side of lesion

Three studies reported depression to be associated with left hemisphere (LH) lesions (Åström et al, 1993; Robinson & Price, 1982; Shimoda & Robinson, 1999) and three reported an association between right hemisphere (RH) lesions and depression (Dam et al, 1989; MacHale, O'Rourke, Wardlaw, & Dennis, 1998; Singh et al, 2000). The remaining studies found no association between hemispheric side of lesion and depression (Berg et al, 2003; Burvill et al, 1996; Collin et al, 1987; Dennis et al, 2000; Desmond et al, 2003; Eastwood et al, 1989; Gainotti et al, 1997; Herrmann et al, 1998; Hosking et al, 2000; House et al, 1990; Kellermann et al, 1999; Ng et al, 1995; Paolucci et al, 1999; Pohjasvaara et al, 1998; Robinson et al, 1983; Sharpe et al, 1990; Spencer et al, 1995).

The studies which found LH lesions to be associated with depression were within the acute period post-stroke (two weeks to two months). Robinson & Price (1982) assessed a diverse sample of patients who were up to 15 years post-stroke. Aström et al (1993) reported LH lesions were more common in those with major depression in hospital, but not up to three years later. Similar findings were reported by Shimoda & Robinson (1999). This suggests the relationship between lesion laterality and depression may only be present early after stroke. Andersen et al (1995) found LH lesions were associated with mild depression. Herrmann et al (1995) reported that

major depression was more common in LH lesions, but lesion laterality was unrelated to self-report scores. This suggests that the assessment method may affect findings. The three studies found RH lesions were associated with depression within the first six months after stroke and Singh et al (2002) found RH lesions were not significant in multivariate analysis. There is limited evidence that lesion laterality is related to depression as a majority of studies failed to support a relationship. Those that found left hemisphere lesions to be significant were in the acute stage (two weeks to two months) and so other factors are likely to be important. Also, most studies excluded aphasic patients which will have excluded patients with LH lesions.

Anterior/posterior lesions

Robinson, Kubos, Starr et al (1984) reported that depression was more severe in patients with left anterior lesions assessed within the first two weeks of stroke. Lesions were classified as anterior if no part exceeded >60% caudally and some part extended <40% rostrally. Two studies found support for this up to two months post-stroke (Åström et al, 1993; Herrmann, Bartels, Schumacher, & Wallesch, 1995). Conversely, Dam et al (1989) found depression was more severe in patients with right anterior lesions using an observer depression rating but not a self-report scale. Six studies found no relationship between depression and left anterior lesions (House et al 1991; Gainotti et al, 1997; Hosking et al, 2000; Paolucci et al, 1999; Pohjasvaara et al, 1998). These studies were between two weeks and five years after stroke, indicating the non significant finding to be consistent over time. The classification of lesions has been criticised. The early definition of 'anterior' (Robinson, Kubos et al, 1984) was subsequently modified. House (1988a) argued that the classification does not map onto anatomical sites, as both cortical and

subcortical lesions could be classified as 'anterior' or 'posterior'. It would be more useful to describe the brain structures that have been damaged (Singh, Herrmann, & Black, 1998). Also, the classification of lesions leads to small groups, for example, House, et al (1990) only had 14 patients with left anterior lesions.

The second consideration is the relationship between the proximity of the lesion to the frontal pole and distress. This distance was defined as the shortest distance between the anterior border of the lesion and the anterior pole of the ipsilateral hemisphere, as a percentage of the overall anteroposterior distance (ANTPER; House et al, 1990). Robinson, Kubos, Starr et al (1984) reported a significant negative correlation between the distance of the lesion from the frontal pole and depression scores in the LH in the first two weeks post-stroke, and this was supported by Eastwood et al (1989). Parikh et al (1987) reported similar findings for patients in hospital but not significant at one and two years. House et al (1990) also found a negative correlation up to six months after stroke. However, Singh et al (2000) found this factor only accounted for 15% of the variance in depression at one month, and was not significant at one year. Sharpe et al (1990) reported no association three to five years after stroke, which supports the suggestion that lesion characteristics are not related to depression in the later stages after stroke.

There is some evidence that in patients with LH lesions there is a negative correlation between ANTPER and depression scores in the early stages after stroke. However, this was not consistently found across studies. The differing times at which patients were assessed may account for discrepant findings. Shimoda and Robinson (1999) found a negative relationship between ANTPER and Present State

Examination scores in patients with LH lesions in hospital and short-term follow-up (three or six months), but not long-term follow-up (one or two years). For RH lesions there was a negative correlation at short-term follow-up but a positive correlation at long-term follow-up. The researchers suggested that there may be a different mechanism in acute and chronic periods (Narushima, Kosier, & Robinson, 2003; Shimoda & Robinson, 1999). The proposed mechanism for the relationship is that neurones containing noradrenaline and serotonin have cell bodies in the brainstem and run anterior to posterior, therefore anterior lesions will disrupt pathways closer to their origin and cause greater depletion in downstream concentrations the neurotransmitters (Robinson, 1998; Narushima et al, 2003). Robinson et al (1998) argued that left hemisphere lesion characteristics were influential only in the acute stages as ischemic injury to the frontal brain regions leads to asymmetric depletion of biogenic amines. However, this hypothesis assumes that monohemispheric systems are lateralised to the left hemisphere, but there is no independent evidence of this (Gainotti, 1992).

Lesion volume

Seven studies reported an association between larger lesion volume and distress in the acute stages and three to five years post-stroke (Shimoda & Robinson, 1999; MacHale et al, 1998; House et al, 1990; Sharpe et al, 1990; Eastwood et al, 1989; Sinyor et al, 1986; Robinson, Kubos, Starr et al, 1984). House et al (1990) found a significant relationship at one year, but not at one month or six months. Robinson et al (1984) reported that lesion volume was positively correlated with depression scores in the LH only at six months post-stroke, but the sample size was small (15 LH and 10 RH) (Robinson et al, 1984). Sharpe et al (1990) found for LH lesions

there was a correlation with the Hospital Anxiety and Depression Scale (HADS), while in the RH a positive correlation was found with the Present State Examination (PSE) at three to five years, suggesting that the assessment method may be relevant. A relationship between lesion volume and depression may result from larger lesions being associated with greater disabilities (Sharpe et al, 1990), which would make lesion location an indirect cause; therefore it would be useful to examine lesion characteristics in the context of other consequences of stroke.

Shimoda and Robinson (1999) posited that mixed findings might be due to a dynamic relationship between lesion volume and depression. They found lesion volume to be negatively correlated with depression scores in the acute period for LH lesions, but at long-term follow up there was a positive relationship for RH lesions. However, four studies found no evidence for a relationship between lesion volume and depression (Herrmann et al, 1995; Aström et al, 1993; Dam et al, 1989; Herrmann et al, 1998). These studies assessed patients in the acute post-stroke period and up to three years post-stroke, contradicting this suggestion.

There is not consistent evidence that particular lesion characteristics are associated with distress. This conclusion is supported by a recent review (Singh et al, 1998) and meta-analysis (Carson et al, 2000). Bhogal et al (2004) concluded that "The association between the site of the stroke lesion and the likelihood of developing depression independent of the clinical consequences remains unproven" (p. 800). Studies are often not comparable for imaging analysis, sample, depression measure and timing of assessment (Singh et al, 1998), and this can influence findings. Not all studies meet the required criteria for the reviews, for example, having a CT visible

single lesion, CT assessed blind to outcome and using standardised depression scales (Singh et al, 1998). One review offered evidence for a relationship between depression and lesion proximity to the frontal pole in the first six months after stroke (Narushima et al, 2003). However, data was duplicated across studies. For example, Robinson's group published six papers with overlapping patients. Early studies were limited as CT scans were often not routinely performed. In one study 23% of patients did not have a lesion visible on the CT scan (Robinson et al, 1983). An inherent problem is that patients with receptive aphasia are frequently excluded due to difficulties in assessing mood; this is likely to result in the exclusion of patients with left posterior lesions (Singh et al, 1998). A second problem is that the requirement for patients to have positive CT scans will bias the sample towards those who are more disabled (Sharpe et al, 1990). Reviews have not taken into account factors such as the source of patients, demographics and assessments used.

1.6.9 Disability

Stroke can cause physical disabilities and it is therefore reasonable to consider whether distress occurs in response to disabilities. In later stages of recovery, when many patients have returned home, distress may develop following the realisation that activities of daily living (ADL) are more difficult to perform than before the stroke; this is consistent with psychological theories of depression (Hosking et al, 1996). This section evaluates the literature on the relationship between disability and distress.

Seventeen studies found a consistent relationship between disability and distress. Ten of these were cross-sectional and seven were longitudinal. Four of the cross-sectional studies assessed patients on rehabilitation or stroke units within the first month of

stroke (Gillen et al, 2001; Kellerman et al, 1999; Ng et al, 1995; Sinyor et al, 1986), but this does not provide information about later after stroke when patients are discharged. The remaining cross-sectional studies assessed patients between three and six months (Burvill et al, 1997; Dennis et al, 2000; Desmond et al, 2003) or one year post-stroke (Kotila et al, 1999). At three to five years after stroke, functional impairment was the strongest predictor of depression reported by Sharpe et al (1994), although patients were required to have a visible lesion on a CT scan, so the sample was biased towards those more severely disabled. Most studies used the Barthel Index and/or the Rankin Scale to assess disability and therefore only considered basic self-care (Barthel Index) or handicap (Rankin Scale). Hosking et al (2000) assessed both basic and extended activities of daily living (EADL) and found that EADL scores but not Barthel Index scores were correlated with depression at three months after stroke. This emphasises that it is necessary to assess ADL extending beyond basic self-care, a factor ignored by most studies, as extended ADL are relevant for patients living in the community. However, EADL scores only accounted for a small proportion of the variance in depression scores in the regression (7%). It is possible that the relationship between the Barthel and mood is mediated by extended activities of daily living.

Seven longitudinal studies found a consistent relationship between disability and distress up to two years after stroke (Herrmann et al, 1998; Kauhanen et al, 1999; Parikh et al, 1987; Pohjasvaara et al, 1998; Robinson, Kubos et al, 1984; Robinson et al, 1983; van de Weg et al, 1999). This suggests that disability remains important in the later stages after stroke. Three studies had overlapping patients (Robinson et al, 1983; Robinson, Kubos, Starr et al, 1984, Parikh et al, 1987) and these found the

correlation increased in the first six months, but decreased at one and two years after stroke, suggesting that other factors may become important. Disability did not explain a large proportion of the variance in distress; the highest correlation was 0.63 at six months after stroke (Robinson, Kubos, Starr et al, 1984). Pohjasvaara et al (1998) and Kotila et al (1999) found disability at three months after stroke was a significant predictor of depression at one to two years indicating that being more disabled early after stroke may be a risk factor for later depression.

Seven studies found partial support for a relationship between disability and distress (Berg et al, 2003; Paradiso et al, 1997; Spencer et al, 1995; Aström et al, 1993; Eastwood et al, 1989; Parikh et al, 1990; Wade et al, 1987). Two of these did not find a significant relationship early after stroke, but did at six months (Spencer et al, 1995), six and 18 months (Berg et al, 2003), and two years after stroke (Parikh et al, 1990). The association between the severity of disability and distress may become significant after the acute stages of recovery as this is when the difficulties caused by disabilities become conspicuous (Berg et al, 2003). Aström et al (1993) supported the idea that other factors are important in later stages of recovery as they found dependence in ADL was the strongest predictor of depression at three months after stroke, but this was not significant after this point. Eastwood et al (1989) found Barthel Index scores to be correlated with distress when assessed on the rehabilitation unit but not at six months after stroke. Similarly, Wade et al (1987) found a decrease in the strength of correlation between ADL scores and distress at six months and one year after in a community study. Correlations only accounted for 5-15% of the total variance in depression sores and they became non significant

when other factors were controlled for, although as it was a community study disability level would be lower than patients recruited from hospital.

Eight studies found no significant relationship between the disability and distress at varying time points after stroke using a range of measures. Five studies recruited patients from hospital or rehabilitation units (Bjerg Bendsen et al, 1997; Cassidy et al, 2004; King et al, 2002; Morris et al, 1990; Starkstein et al, 1989) and three assessed a mixture of inpatients and outpatients (Andersen et al, 1995; Dam et al, 1989; Robinson & Price, 1982). All but one of the studies was cross-sectional. King et al (2002) followed up patients from a rehabilitation unit for two years after stroke, although due to attrition the final sample size had halved.

Two-thirds of the studies reviewed found evidence for a relationship between disability and distress, namely that patients who were more disabled were more distressed or more likely to be distressed. It is therefore important to assess disability level when examining factors related to distress after stroke. The relationship was strongest at about three to six months after stroke, at which time patients are likely to be adjusting to returning to the community. This fits with psychological theories of depression. Negative cognitions about the self, the world and the future may be related to disability, e.g. *"I'm no good at anything"*. The current situation may be viewed pessimistically in terms of the obstacles that the disability causes. If patients are disabled then they may receive less positive reinforcement if there is a loss of pleasurable activities, and this will become more apparent when patients are discharged (behavioural theory of depression). Patients who require assistance in daily living due to their disabilities may feel dependent or helpless. The level of disability did not explain a large proportion of variance in distress when included in

predictive models (Berg et al, 2003; Hosking et al, 2000; Wade et al, 1987), and there is evidence that social variables are important in later stages of recovery (Spencer et al, 1995; Aström et al, 1993). For patients residing in the community it is informative to have a measure of a broader range of more complex activities such as extended ADL.

1.6.10 Aphasia

Aphasia can be defined most simply as a loss or impairment of language caused by brain damage (Benson, 1973). About one-third of stroke patients will develop aphasia (Parr, Byng, & Gilpin, 1997). Aphasia can be broadly categorised as receptive aphasia (also referred to as Wernicke's aphasia or fluent aphasia), which includes comprehension deficits, that is, difficulty with understanding language, and expressive aphasia (also referred to as Broca's or nonfluent aphasia), which is problems with the spoken production of language (Spencer et al, 1997). Language function is lateralised to the left hemisphere in most individuals, and so lesions to the left temporal-parietal lobe will produce severe aphasia (Benson, 1973). Aphasia can affect all modalities of language including expression and comprehension of speech, reading, writing and gesture and it can be very mild or severe (Code & Herrmann, 2003). Communication is important for social roles and relationships and everyday functions require communication. Consequently, aphasia results in a sudden inability to function in many activities of daily life, such as leisure, occupational and social activities (Code, Hemsley, & Herrmann, 1999). For example, Code (2003) found that in chronic aphasics, aphasia severity was the most important factor impacting upon the amount of time spent in social activity, and communicative effectiveness was correlated with the number of hours spent out of the house. Herrmann and Wallesch (1989) found that chronic aphasics reported considerable psychosocial changes in

professional, social, family and psychological domains. Much of our happiness and sadness derives from interactions with others (Code & Herrmann, 2003) and language is of such importance that the loss or impairment of language may elicit severe emotional reactions (Robinson & Benson, 1981). The impact of aphasia on distress is therefore an important area of research.

Language is fundamental for the assessment of subjective symptoms of distress. This presents an obvious problem with aphasic patients. As aphasic patients cannot readily be assessed on many existing self-report measures of distress, individuals with severe comprehension deficits (and therefore left posterior lesions) are frequently excluded from research (Damecour & Caplan, 1991). It is possible that excluded patients were distressed and these patients have been under-represented in prevalence estimates of distress. This may have skewed the association between depression and lesion location to more frontal brain regions (Starkstein & Robinson, 1988). When aphasic patients are excluded it is not clear with what criteria patients were classified as aphasic, and whether this was formally assessed. Ideally, when studying brain-injured patients, they should be systematically screened for language impairments (Spencer et al, 1997).

Robinson and Benson (1981) assessed depression in 25 male inpatients (18 were stroke) using a visual analogue mood scale, the Hamilton Depression Scale, and a nurses' rating scale and the Zung Self Rating Depression scale was read to patients. Almost half of patients showed significant depression, although the validity of the assessments for aphasic patients was not evaluated. Depression frequency and severity were greater in patients with nonfluent aphasia, which was supported by the

findings of Herrmann et al (1993). It was proposed that nonfluent aphasia may be more strongly associated with depression as these patients have a greater awareness of their impairments. This demonstrates that distress is common in aphasia, although the study by Robinson and Benson (1981) was a small sample of men only. In contrast, Damecour and Caplan (1991) found that depression rated by observers was more severe in those with fluent aphasia, and this was unaffected by whether patients were acute or chronic. It is possible that the contrasting findings were due to different samples and assessments.

Kauhanen et al (2000) found that two-thirds of aphasic patients met DSM-III-R criteria for depression (major or minor) up to one year after stroke, and this was significantly greater than those without aphasia. Major depression increased between three months and one year, this may be as the impact of aphasia on everyday activities persists. However, the effect of aphasia on depression was not significant when the effects of age, stroke severity and disability were controlled for, suggesting that aphasia is not the only factor related to distress. DSM-III-R criteria were assessed through patient interview and information from relatives and hospital staff, but the reliability and validity of applying these criteria to neurological patients with communication problems was not evaluated. Herrmann et al (1993) compared 21 patients with acute aphasia (less than three months) with 12 patients with chronic aphasia (more than six months). Distress scores were non significantly higher in the chronic group. Astrom et al (1993) reported aphasia to be a significant predictor of major depression at one and three months after stroke but was not significant after this time, suggesting other factors are also relevant.

There is evidence that distress is common in aphasic patients and this remains for the first year after stroke. However, some of these findings are based on small sample sizes from cross-sectional studies. Longitudinal studies are needed in larger samples to assess the impact of aphasia on distress in the acute and later stages of recovery, using standardised assessments. Despite the methodological limitations discussed, the exclusion of aphasic patients from studies may underestimate the prevalence distress and limits our understanding of risk factors for distress.

1.6.11 Coping

Rehabilitation and adjustment to neurological illness, such as a stroke, are influenced not only by the nature of the illness itself, but also by the coping strategies used by the patient (Herrmann et al, 2000). A stroke is a major life event that requires strategies to cope with the motor, cognitive and emotional consequences (Finset & Andersson, 2000). It was hypothesised that those who employ more effective coping strategies are likely to have lower levels of distress (Rohde, Lewinsohn, Tilson, & Seeley, 1990). Maladaptive coping can have an adverse effect on physical and emotional health (Shaw, 1999). It is therefore reasonable to hypothesise that maladaptive coping strategies may be associated with distress. This section will introduce the concept of coping and review the literature on the relationship between coping and distress after stroke.

Coping is defined as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984 p.141). The most influential model is Lazarus and Folkman's (1984) interactional model of stress. This proposed that coping efforts result from continuous appraisals and reappraisals of the

changing person-environment relationship (Folkman & Lazarus, 1988). Emotional reactions depend on the appraisal of the event. Primary appraisal refers to the evaluating the significance of the event for the person's well-being, and secondary appraisal is an assessment of coping resources (psychological, social and material) that the individual has (Gage, 1991; Lowe, Norman, & Bennett, 2000). Primary and secondary appraisals interact to determine the individual's reaction to the stressor (coping), but they do not occur in a fixed temporal order (Gage, 1991). Lazarus and Folkman (1984) differentiated between problem-focused coping, which is efforts to reduce or change the demands of a stressful experience, and emotion-focused coping which is efforts to reduce emotional distress or divert attention away from distress (e.g. seeking emotional support, denial, or reinterpreting the situation). A distinction has also been made between approach-oriented coping and avoidant coping. Approach coping is concerned with active attempts to manage the stressor and positively reinterpret the situation, such as expression of emotions and seeking social support (Finset & Andersson, 2000). Avoidant coping is orientation away from the stressor, for example, wishful thinking, denial, behavioural disengagement and self-distraction (Zeidner & Saklofske, 1996). Avoidant coping has been found to be related to distress and negative affectivity (Rohde et al, 1990).

Coping is viewed as a mediator of emotional response: the stressful transaction is appraised as being significant for the individual, this influences coping, which in turn changes the person-environment relationship and emotional response (Lazarus & Folkman, 1984; Folkman & Lazarus, 1988). There are three ways in which coping can affect emotion (Folkman & Lazarus, 1988). Coping efforts can divert attention towards the stressor in order to make a plan of action; this may reduce distress unless

nothing can change the situation. Alternatively, efforts can divert attention, such as wishful thinking. Avoidant strategies can initially reduce distress but this can be maladaptive if there is a problem requiring attention. Secondly, the subjective meaning of the person-environment transaction can be changed, such as denial or making light of the situation. Positive reappraisal of the situation can be more advantageous as it can turn the 'threat' to a 'challenge'. Thirdly, the person-environment can be changed through problem-focused strategies, and the emotional response will depend upon the evaluation of the outcome. It is expected that planful problem-solving and positive reappraisal are associated with more positive emotions (Lazarus, 1993). Direct efforts such as problem-solving strategies can increase feelings of control. Rosenberg, Peterson and Hayes (1987) argued that those with higher levels of depression will exhibit more avoidant strategies due to expectations of helplessness.

The relationship between coping and distress has been studied in a variety of chronic conditions. Emotion-focused coping significantly correlated with psychological distress in multiple sclerosis patients (Jean, Paul, & Beatty, 1999) and myocardial infarction patients (Bennett, Lowe, Mayfield, & Morgan, 1999; Lowe et al, 2000). In spinal cord injury (SCI) patients depression was associated with denial, behavioural and mental disengagement and alcohol/drug use, while acceptance was correlated with lower depression (Kennedy et al, 2000). It follows that coping may be related to distress following stroke, but this has not been widely examined. Sinyor et al (1986) found depression was negatively correlated with endorsement of rational cognitions (e.g. "I take things one step at a time") and behavioural action. The researchers suggested that the coping efforts associated with depression might reflect less

participation in rehabilitation. Finset and Andersson (2000) found avoidant coping was associated with depression, in stroke and brain injury patients in a rehabilitation hospital.

These studies were performed early after stroke and were cross-sectional. Rochette and Derosiers (2002) interviewed stroke patients after discharge from rehabilitation and six months later. At six months, depression scores were correlated with escape-avoidance and magical thinking. However, patients were not interviewed in hospital which would have provided information about the stability and predictive value of coping strategies. King et al (2002) interviewed stroke patients prior to discharge from hospital (Time 1) and up to two years later (Time 2). At Time 1 depression was associated with avoidant coping but at Time 2 coping strategies were not predictive of depression, although complete data was not available for all patients. Problem-focused strategies were therefore beneficial only during the early stages of adaptation. Similarly, Herrmann et al (1997) found coping styles were not correlated with depression in patients at least six months post-stroke. The studies reviewed here have suggested that problem-focused and approach-oriented coping are related to lower levels of depression early after stroke, this may be the time at which patients are encountering the most problems to address when they are beginning to adjust to their post-stroke lifestyle.

Lazarus and Folkman (1984) posited that the coping strategy employed would be in part a function of the resources available. Social support is a potential resource, however the relationship between coping and social support has not been widely studied. It is useful to consider the relationships between these constructs as they

may be amenable to intervention. Thoits (1986) proposed that social support could be conceptualised as coping assistance, as social support and coping are similar behaviours, except that coping is initiated by the individual, while social support is initiated by others. For example, problem-focused coping and instrumental social support are analogous, and emotion-focused coping and emotional support have the common aim of ameliorating negative feelings (Thoits, 1986). The interaction between coping and social support was assessed in a cross-sectional study of patients up to one year post-stroke, with depression as an indicator of coping effectiveness (Boynton De Sepulveda & Chang, 1994). Perceived availability and effectiveness of social support were proposed to be coping resources which would influence coping behaviours, and in turn coping effectiveness, but this was not found. Depression was associated with escape-avoidance, emotion-focused coping and accepting responsibility but in the overall model coping behaviour was not significantly related to coping effectiveness. Boynton et al (1994) included patients at varying stages of recovery which may have influenced findings and the previous studies discussed found coping was not related to distress after about six months post-stroke. The interaction between social support, coping and distress should be examined longitudinally. The relationship between coping and social support has not been widely studied in stroke. Further studies are required to explore the relationships between these constructs; coping may sensitise the individual to the availability of social support, or the perceived availability of support influences secondary appraisal and subsequent coping (McColl et al, 1995).

Coping may also be influenced by locus of control, as locus of control may be related to secondary appraisal. It is predicted that problem-focused strategies are associated

with a greater sense of self-control, as the individual believes they can change the stressful situation (Boynton et al, 1994). Conversely, emotion-focused strategies will dominate when the situation appears to be beyond the person's control. Greater perceived control is likely to result in the use of problem-focused coping, and as individuals believe they can cope with the stressor, coping efforts are more likely to be successful (Kendall & Terry, 1996). Internal locus of control has been associated with more effective coping and better adaptation to long-term disability, however, locus of control and coping should be examined in the context of environmental characteristics such as the social support network (Maas et al, 1988).

The relationship between coping strategies and distress has not been widely studied in stroke. This is an important area of study as coping strategies are amenable to intervention. The reviewed provide some evidence to suggest that those who employ more adaptive coping strategies are less likely to be distressed in first six months after stroke. Problem-focused strategies seem to be associated with more favourable emotional outcomes, and it is hypothesised that coping strategies could also be influenced by a greater degree of internal locus of control and perception of social support. Further longitudinal studies are required to evaluate the influence of coping on depression after stroke, and the interaction between coping and factors such as social support and locus of control.

1.6.12 Locus of Control

Individual vary in their adaptation to an acquired physical disability and this will impact upon physical and psychological recovery. The way in which a person reacts to and manages their situation will be influenced by the degree of control they perceive that they have over processes and outcomes. Locus of control (LOC) is

"...the individual's perceptions of control over reinforcements and reflects the belief in the ability to manipulate environmental conditions affecting the individual" (Martz, Livneh, & Turpin, 2000 p.14). This can be described as *internal,* whereby someone believes that reinforcements (or outcomes) are contingent upon their own behaviour or characteristics, or it may be *external* where fate, chance or powerful others are perceived to control reinforcements or outcomes (Maas, de Jonge, & McKenna, 1988).

Locus of control may have implications for motivation in rehabilitation (Maas et al, 1988). There is evidence that an internal locus of control is associated with increased acceptance of disability (Martz et al, 2000). Many patients believe that doctors are responsible for addressing health problems, while others believe that responsibility for one's health lies within the individual (Wallston & Wallston, 1982). An unexpected illness is likely to challenge the belief one has about the degree of control that they have over their health (Blair et al, 1999). Perception of control is likely to be affected by being in a hospital environment and receiving therapy (Morrison, Johnston, & MacWalter, 2000). This section will review the literature that has examined relationships between LOC, rehabilitation and distress after stroke.

There is an implicit assumption that an internal locus of control is good and evidence suggests an internal locus of control is related to more positive outcomes in rehabilitation (Shaw, 1999). Those who perceive that they have control over their health will be motivated to play an active role in their rehabilitation, while an external locus of control will encourage passivity (Blair et al, 1999). 'Internals' are considered to be more competent; they take responsibility for their actions and will

take steps in response to aversive life situations (Wallston & Wallston, 1982). One mechanism is through seeking information and being involved in treatment. Individuals with an internal LOC may have better adjustment to disability as they are able to set new goals in response to problems (Martz et al, 2000). Partridge and Johnston (1989) found that stroke and wrist fracture patients with an internal locus of control had faster and better progress in recovery than those with an external locus of control. Johnston, Morrison, MacWalter and Partridge (1999) extended these findings in a study of a larger sample of stroke patients. Recovery locus of control scores at one-month post-stroke (but not at recruitment 10-20 days after stroke) predicted recovery at six months.

Locus of control has also been linked to distress, as an external locus of control is likely to be related to feelings of helplessness. Perceived control can be an important predictor of affective state following disability or illness (Schulz et al, 1994). External LOC has been found to be associated with increased distress in myocardial infarction patients (Blair et al, 1999) and patients with spinal cord injury (Macleod & Macleod, 1998). A meta-analysis reported a consistent relationship between an external LOC and depression (Benassi, Sweeny, & Dufour, 1988) but this was not concerned specifically with disability or illness.

In stroke patients Morrison et al (2000) found recovery locus of control scores at one month after discharge were negatively correlated with residual depression scores at six months (with residuals greater than zero representing greater depression than predicted by initial scores), although this was not significant in regression analysis. This suggests that locus of control alone is not sufficient to explain distress after

stroke. Sinyor et al (1986) found stroke patients with an external health locus of control to have greater hopelessness, but locus of control scores did not differ significantly between depressed and non depressed patients. However, patients were assessed within weeks of their stroke and they may still be forming illness representations. In a community study an external locus of control was associated with a higher risk of depression, although the time after stroke was not specified (Beekman et al, 1998). Further longitudinal studies are required to ascertain whether locus of control changes following hospitalisation, and whether there is a corresponding change in mood.

The literature reviewed provides some evidence that an external LOC is associated with distress after stroke, but this has not been widely studied. However, Morrison et al (1999) found that locus of control was not a significant predictor of depression in the regression model. This suggests it will be more informative to examine locus of control in the context of other psychosocial factors such as social support and coping.

1.6.13 Social Support

"Social support most commonly refers to functions performed for a distressed individual by significant others such as family members, friends, co-workers, relatives and neighbours" (Thoits, 1986 p.417). Social support can range from practical assistance from a neighbour to a confiding relationship (Knapp & Hewison, 1998). Being associated with others is an important experience from which we derive self-image, self-esteem, and affection and these resources are significant during crisis and major transitions (Evans & Northwood, 1983). Patients living with limitations imposed by a chronic condition will depend upon their social environment for support (Schreurs & de Ridder, 1997). Social support can serve many functions:

expressing positive affect, provision of material aid or information, expression of feelings and providing reassurance (Wortman & Conway, 1985). For these reasons, social support has been studied in stroke. This section will describe the components of social support and will review studies investigating the relationship between social support and mood following stroke.

A distinction has been made between *received support* and *perceived support* (McColl, 1995). Received support refers to a behavioural measure of support, while the latter is a subjective measure of the experience of support. It is thought that the supportive actions of others augment coping performance, while perceptions of available support help threatening events be appraised as less stressful (Lakey & Cohen, 2000). Several taxonomies of social support exist: emotional support includes providing assurance and comfort, positive feedback and the opportunity to express negative feelings; informational support can involve giving advice and guidance; tangible or instrumental support refers to practical assistance such as help with household tasks. Emotional support can provide reassurance and encouragement, and enhance self-efficacy (Glass & Maddox, 1992). The effects of support are likely to be stronger if support matches the demands of the stressor and in order to be beneficial the individual must be able to make use of the support. Also significant is satisfaction with support. This requires "...an internal assessment of the extent to which social support fulfils needs, complements individual coping, or meets expectations." (McColl, 1995 p.317).

Stroke survivors experience several sources of stress including the onset of illness and changes in functional status and social support may aid adaptation (Friedland &

McColl, 1987), particularly when the patient no longer receives formal support. The level of support is important as it can influence whether the patient is discharged home (Thompson, Sobolew-Shibin, Graham, & Janigan, 1989). It is also possible that patients with a disability may have difficulty obtaining support as those around them can react negatively or become frustrated (Wortman & Conway, 1985). Social support can also have negative effects in stroke, as overprotection might elicit helplessness (Thompson et al, 1989). For example, a community study of older adults found support increased feelings of control up to a threshold, beyond which it lead to dependence and decreased feelings of control (Krause, 1987).

The 'buffering hypothesis' refers to the idea that social support buffers the perceived impact of a stressful event, thereby reducing the probability of negative mental health outcomes. According to this hypothesis, social support is only beneficial for those experiencing stressful situations (Schreurs & de Ridder, 1997). For example, it can make threatening experiences seem less harmful, or it can provide resources for coping (Lazarus & Folkman, 1984). Knapp and Hewison (1998) found support for the buffering hypothesis in stroke patients, more specifically for close attachment relationships, six months after discharge from hospital. However, the sample size was small (n=30) and to be eligible for inclusion patients had to have a named carer. Satisfaction with support was unrelated to mood. Spencer et al (1995) reported that greater satisfaction with the amount of social contact at six months after stroke was related to lower levels depression, although all patients had a primary support person. Having a small social network has been reported as a predictor of depression up to three years post-stroke (Aström et al, 1993). In a community sample of patients up to one year after stroke social resources buffered the effects of the stressor on mood in

those who were not severely disabled (Boynton et al, 1994); it is possible that those more severely disabled felt inadequate and helpless. Satisfaction with and availability of support has been found to correlate with greater depression two years after discharge (King et al, 2002). Similarly, Friedland and McColl (1987) found various aspects of support (e.g. personal, friend and community) to be protective against poorer psychosocial adjustment at two years post-stroke. These studies indicate that social support is related to distress not only in the early stages after stroke, but also in the first two years when patients are living in the community. Lower perceived social support at two months after stroke was found to be related to more severe and chronic depression (Morris, Robinson, Raphael, & Bishop, 1991). It could be argued that those who were depressed had a lower perception of support, however the patients who were not depressed initially but rated support as inadequate were more likely to become depressed at follow-up.

There is evidence that lower perceived social support and lower satisfaction with social support can have negative effects on distress after stroke. Further studies are required as social withdrawal is a consequence of distress; therefore the direction of the relationship between mood and social support needs to be delineated. Also, assessment of social support should measure multiple dimensions of support, namely amount, perception of support and satisfaction with support. Some of the previous studies were limited as they required patients to have a primary support person. In the elderly increases in social support were found to be related to increased feelings of control, but beyond a threshold point further support decreased feelings of control (Krause, 1987). In cardiac patients, positive social context (high social support and low social stressors) predicted. lower levels of depression through the use of adaptive

coping strategies (Holahan, Moos, Holahan, & Brennan, 1997). This suggests that it would be informative to assess longitudinally the constructs of locus of control, coping and social support.

1.7 Development of a theoretical framework for the study of emotional distress after stroke

It was shown in the literature review that distress is common after stroke. Despite variability in methods and prevalence reports across studies, about one third of stroke patients recruited from hospital become distressed in the acute stages following stroke, this rate is slightly lower for community samples, and the higher prevalence from hospital/rehabilitation settings is sustained over time. There is also evidence that emotional distress can have a negative impact on rehabilitation and quality of life. Therefore, research efforts should be directed towards the understanding of what factors are associated with emotional distress after stroke, in order to identify patients at risk of becoming distressed and to develop effective interventions.

This thesis has considered the extent to which psychological models of distress, in particular the cognitive and behavioural models, can be applied to stroke. Several biological and psychological factors and characteristics were identified in the literature that have been found in some studies to be associated with distress after stroke. However, while several studies have been conducted many only look at a few factors in isolation, and without a clear theoretical rationale, and do not consider how these factors may interrelate. This section will use the findings from the literature review to develop a theoretical framework for the study of emotional distress after stroke.

There are several justifications for developing and evaluating a framework for the study of emotional distress following stroke. The first of these is theoretical: it will provide an integration of the literature and identify those factors that are likely to be

associated with distress. This can serve as a framework to investigate emotional distress following stroke and identify factors to be explored further. The second reason is that it will have implications for clinical practice. The evaluation of the framework will be important for identifying patients at risk of becoming distressed, and it can be used to inform the development of preventative and therapeutic interventions that can be incorporated into patient care. The identification of relevant non-neurological factors may influence rehabilitation programmes through therapeutic techniques.

Some researchers have considered models of distress specific to stroke. Herrmann and Wallsesch (1993) proposed a model of depression after stroke which incorporated both neuroanatomical and psychosocial factors. Causes of depression were divided into primary, secondary and tertiary, and map onto different phases of rehabilitation. Organic factors were proposed to be the main cause of depression early after stroke, and psychosocial factors are influential in later stages. The researcher proposed that there are primary, secondary and tertiary causes. Primary causes - in the acute stages (0-3 months) are premorbid disposition (e.g. psychiatric history) and lesion location, with patients having a middle cerebral artery infarction being most vulnerable. Secondary causes – psychoreactive factors become important in the first six months after stroke. Patients vulnerable to depression are those who initially denied the consequences of the stroke and become faced with the impact of their disabilities and patients who had unrealistic expectations of recovery. Tertiary factors – factors relevant during the transition from inpatient care to outpatient treatment. When patients attempts to return to their pre-morbid lifestyle the impact of their disability becomes apparent.

Gainotti et al (1999) hypothesised that if the model of Herrmann and Wallesch (1993) is correct in predicting that organic factors are causal of depression in the acute stages and psychosocial factors are important in later stages, then major post-stroke depression should be phenomenologically similar to endogenous major depression early after stroke, but not later on. These hypotheses were tested in a cross-sectional sample of stroke patients assessed between two months and six months after stroke, and 30 patients on a psychiatric ward with endogenous major depression for comparison. Patients were assessed on the Hamilton Rating Scale for Depression and the Post-Stroke Depression Rating Scale (PSDRS), the latter scale developed by Gainotti et al (1997) to assess symptoms of depression in stroke patients. Symptom profiles on the PSDRS did not differ between depressed stroke patients at the three time points, while symptom profiles for endogenous depression and major post-stroke depression were not comparable. Lesion location was unrelated to depression.

Gainotti et al (1999) argued that these findings do not correspond with the model of Herrmann and Wallsech (1993), as lesion location was unrelated to depression and post-stroke and endogenous major depression did not have comparable symptom profiles. They concluded that the results are consistent with a psychological model, namely depression is reaction to the consequences of the stroke. Also, there was little evidence for the lesion location hypothesis in the literature review in this thesis (Carson, 2000; Singh et al, 1998) and Herrmann and Wallsesch (1993) did not detail what psychological factors were important and how these could be assessed. Future models need to consider the role of psychological factors in more detail. However,

Ramasubbu (2000) argued it was inevitable that patients with endogenous depression were found to have more endogenous symptoms. Also, the PSDRS was developed for stroke, and items may not be applicable to endogenous depression. The study is restricted as it was cross-sectional and the authors were unable to assess the evolution of depression. The study would need to be conducted in a longitudinal cohort of stroke patients and assess psychological factors to explore the assertion of Gainotti et al (1999) that there is a psychological explanation for depression.

The theoretical framework proposed for investigation in this thesis is shown in Figure 1.3 (page 111). This framework has endeavoured to integrate the theories and findings identified in the literature. The framework considers five areas to be assessed in the study of distress after stroke: background information, demographic characteristics, stroke characteristics, disability level and psychosocial variables.

Stroke characteristics encompass lesion location and the severity of stroke. The location of the lesion will influence the level of disability, which in turn may be related to distress. For example, a left hemisphere lesion is likely to be associated with communication impairment and a more severe stroke, such as a TACS, will be related to more severe impairments. In the literature there was little evidence for a relationship between lesion location and distress. However, it is important to include in the framework as it has been so widely discussed in the literature and it would be informative to replicate a non significant finding in a study which considered other possible risk factors. Stroke characteristics should be recorded as this describes the sample and allows comparison to other studies. Therefore it is proposed that lesion location will not be strongly related to distress.

Background factors include pre-stroke ADL, a history of depression and having a previous stroke. There was some evidence from the literature that having suffered a previous stroke was associated with low mood following a subsequent stroke, although it was difficult to draw conclusions as many studies exclude patients who have had a previous stroke. There was mixed evidence for an association between a pre-stroke history of depression and distress after stroke, although similarly patients with a pre-stoke history of depression are often excluded. It is important to include patients who have had a previous stroke and those with a history of depression as this will provide a more representative sample. Pre-stroke ADL should be recorded as individuals who were more active prior to their stroke may be more distressed as the stroke will have a greater impact on their life, as Lewinsohn et al (1985) proposed that distress results from the impact of a stressor on everyday (scripted) activities due to reduced reinforcement. It is therefore predicted that those with a higher activity level pre-stroke will be more distressed. Background variables should be recorded as they describe the sample and may influence how an individual reacts to and copes with the impact of stroke. It is predicted that having a previous stroke and a history of depression will not account for a large amount of variance in distress as these have not been found in the literature to be consistently related to distress.

Demographic variables of age, gender, marital status and living arrangements are included. It is important that basic demographic information is recorded to describe the sample being studied and identify whether it is comparable to other studies. The aforementioned demographic characteristics have been considered in the literature. A majority of studies found age to be unrelated to distress. Most studies also found

gender to be unrelated to distress, although there was a trend across some studies for women to be more likely to be distressed. Marital status and living arrangements, where analysed, were generally unrelated to distress. It is predicted that demographic variables will be weakly or not significantly related to distress.

The disability caused by the stroke is broken into three components – personal ADL, extended ADL and aphasia. Independence in personal ADL and extended ADL, as there was some evidence in the literature review that physical disability was related to distress. Most of the literature evaluating the relationship between disability and distress only considered personal ADL, such as continence, washing and dressing. It would also be informative to measure independence in extended ADL as these are applicable when the patient has been discharged from hospital.

The impact of the stroke on activity level are important, with psychosocial variables proposed to affect how an individual reacts to and copes with the impact of the stroke. Most studies have excluded patients with aphasia but those studies that have included aphasic patients found distress to be common in patients with aphasia (Robinson & Benson, 1981; Kauhanen et al, 2000). For this reason and the finding that severity of aphasia is an important factor predicting the amount of time spent out of the house and in social activity (Code, 2003) it is important to assess aphasia. Aphasia may cause the individual to be unable to interact with others and everyday activities such as reading the newspaper and socialising with friends may become difficult. Consequently, the individual may be self-critical and experience feelings of hopelessness. The behavioural approach would predict that the reduced interaction with the environment and those around them due to communication impairment or

dependence in personal and extended ADL, leads to a reduced positive reinforcement and positive feedback and an increased rate of aversive experience (e.g. feelings of failure). Lewinson et al (1985) proposed that this leads to increased self-awareness, self-criticism and self-expectancies which in turn leads to increased depression. The impact of the stroke may also activate negative self-schemas and thought patterns being characterised by a negative cognitive triad of thoughts about the self, the world and the future (Grober et al, 1993; Noble, 1993), which are in turn associated with depressed mood. It is therefore proposed that dependence in personal ADL, dependence in extended ADL and aphasia will be related to distress.

Psychosocial variables are included as factors that may influence an individual's emotional response to stroke. The three main factors that were identified in the literature were locus of control, coping and social support. There is evidence that internality of locus of control is related to greater emotional distress after stroke (Sinyor et al, 1986, Morrison et al, 2000). Maladaptive coping, such as denial and avoidance is thought to have an adverse effect on emotional outcome (Shaw, 1999). Poorer social resources (Boynton et al, 1994), having a small social network (Astrom et al, 1993), lower satisfaction with the amount of social contact (Spencer et al, 1995) and lower perception of social support (Morris et al, 1991) have all been reported to be associated with a greater risk of emotional distress following stroke. Therefore, it is predicted that externality of locus of control, maladaptive coping, low social support and dissatisfaction with social support will be associated with distress. These are important constructs to evaluate as they are amenable to psychological intervention. There is also some evidence that negative cognitions are associated with distress after stroke (Noble, 1993; Nicholl et al, 2002) but further work is

required to develop a relevant assessment of stroke-related cognitions to explore this further.

The model presented here is proposed as a theoretical framework to direct the research conducted in this thesis. It is not an exhaustive model as there may be inter-relationships between constructs, for example social support may vary according to the age and gender of the patient. Also, it is possible that background variables, demographic characteristics and psychosocial variables have a direct effect on distress or an indirect effect by influencing how an individual reacts to and copes with their stroke (and so are included as dashed lines in the model). However, if many possible inter-relationships were included then the model would be too complex to investigate and interpret. Also, due to the nature of the population it would be both impractical and unethical to require the patient to complete an extensive battery of assessments. The framework will direct the research conducted in this thesis. The constructs presented in the framework need to be assessed longitudinally in a sample of stroke patients to identify which are significantly associated with distress. Identification of factors significantly associated with emotional distress will provide useful information for identifying patients at risk of becoming distressed and will guide recommendations for appropriate interventions.

This framework and the work presented in this thesis are required as previous research has often not been based on a theoretical rationale. Also previous studies have only considered a few factors in isolation, particularly with regard to psychosocial variables. It is therefore important to assess the factors from the

framework in one study to identify which are significantly related to distress after stroke.

This thesis consisted of three studies. The first study involved the development and validation of a measure of stroke related cognitions in order to evaluate the cognitive model of depression in stroke. The second study was a secondary analysis from a study of cognitive behaviour therapy to treat depression after stroke. This data were used to explore factors related to depression and acted as a pilot study. The third study was the main focus of this thesis and was concerned with evaluating the constructs from the theoretical framework to identify factors predicting distress in the first six months after stroke.

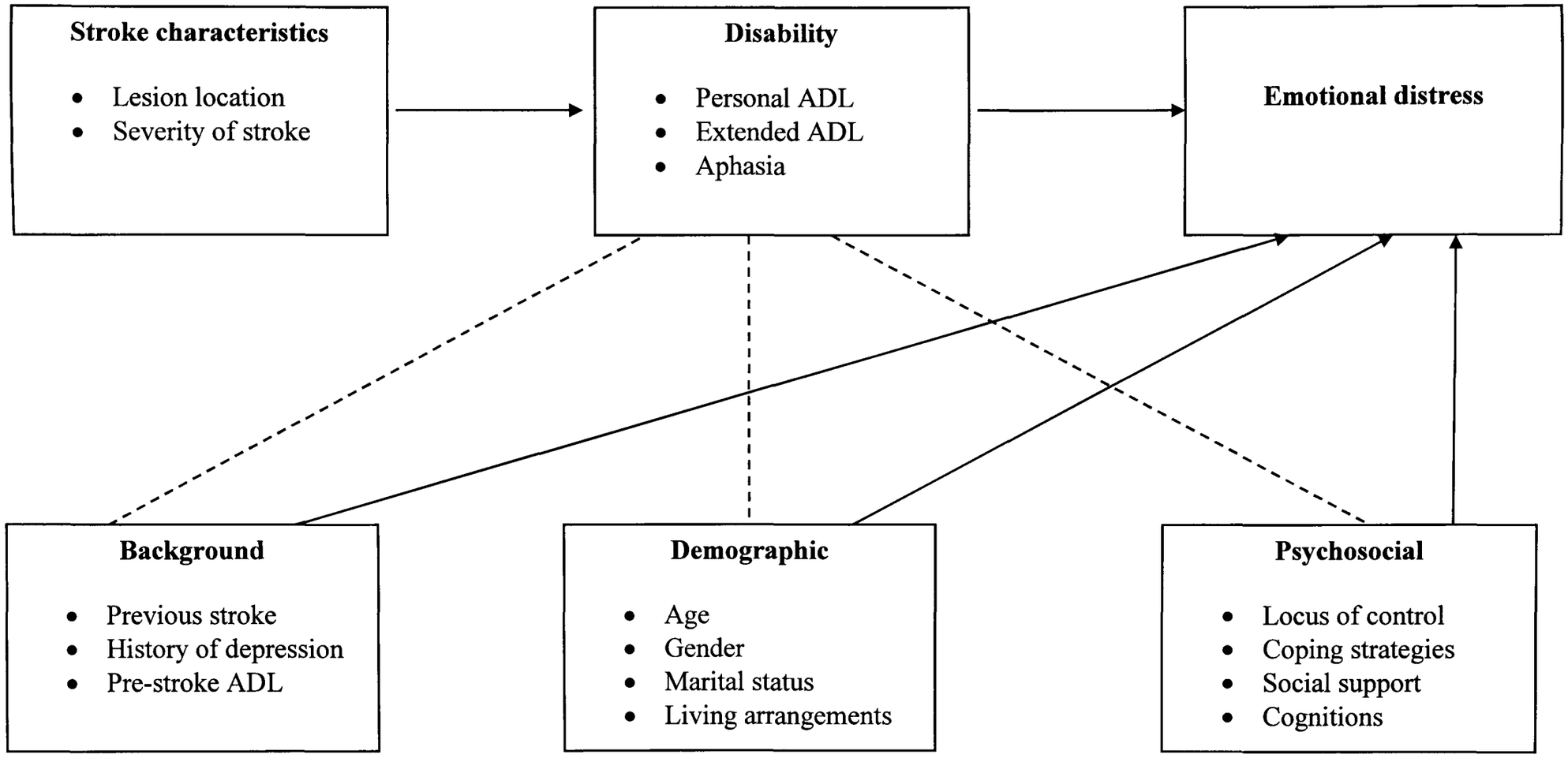


Figure 1.3 Theoretical framework for the study of emotional distress following stroke

- - - - - - - Indicates variables that may moderate the relationship between disability and distress

2 CHAPTER 2 - DEVELOPMENT AND VALIDATION OF THE STROKE COGNITIONS QUESTIONNAIRE REVISED (SCQR)

2.1 Introduction

The cognitive model of depression was outlined in the literature review and cognitions were included in the theoretical framework for the study of distress after stroke. The cognitive model has not been widely studied in stroke and other medical populations. Previous studies in these populations were limited as they used cognitions measures that were developed for psychiatric samples (Clark et al, 1998; Noble, 1993) and so the items may not have assessed cognitions relevant to the population being studied. Reliability and validity data of cognitions scales have largely been collected on normal to mildly depressed college students (Crandell & Chambless, 1986). Existing scales to assess depression severity measure physical, behavioural, affective and cognitive symptoms, but do not assess specific cognitions that may be associated with depression (Zauszniewski, 1995). Also, existing cognitions scales have focused almost exclusively on negative cognitions. It was recommended that researchers and therapists interested in the assessment and treatment of depression should also consider the absence or decrement of positive cognitions (Clark et al, 1999). Ingram and Wisnicki (1988) developed the Positive Automatic Thoughts Questionnaire (ATQ-P) to investigate the role of positive thinking in depression, although this was constructed and evaluated on a sample of undergraduate students and so items may not be applicable to stroke patients. Clark et al (1999) advised caution against applying a cognitions measure from one population to another as negative thinking can be idiosyncratic and cognitive themes need to be relevant to the population under study. Nicholl et al (2002) developed the Stroke Cognitions Questionnaire (SCQ) to assess the frequency of positive and

negative cognitions that were relevant to stroke patients. The SCQ (Nicholl et al, 2002) consisted of 17 statements, 12 negative and five positive which were identified from the review of treatment notes of stroke patients who received cognitive behaviour therapy for depression (Lincoln et al, 1997). For each statement patients were required to state whether they had the thought 'often', 'sometimes', 'rarely' or 'never' in the past month and scores can be calculated for the total and for positive and negative cognitions. Nicholl et al (2002) found patients identified as depressed on the Beck Depression Inventory reported negative cognitions more frequently and positive cognitions less frequently than stroke patients who were not depressed. However, the study was limited as treatment notes were only reviewed from a small sample of patients (nine patients) and test-retest and inter-rater reliability was not assessed. Further development of the scale is required to take account of these limitations in order to support its use as a valid measure of depression related cognitions in stroke patients. The scale can then be used to evaluate the cognitive model of depression in stroke.

Investigation of the cognitions of stroke patients will also provide important information regarding the treatment of depression after stroke. There is widespread agreement that emotional disorder is common following stroke, however little focus has been give to the evaluation of psychological interventions to treat depressed mood in stroke patients. Early diagnosis and treatment is required to prevent depression from becoming chronic (Andersen, 1997), yet most patients do not receive any medication or therapy for their depressive disorders (e.g. Wade et al, 1987). There are two main approaches to the treatment of depression after stroke. The first is antidepressant medication. Lipsey et al (1984) found nortriptyline to be

beneficial compared to a placebo but one-third of patients discontinued medication or suffered side effects. Also, antidepressant medication may not be appropriate for all patients due to polypharmacy and drug interactions and poor compliance by patients. Consequently, it has been argued that there is an urgent need to develop and evaluate psychological treatments for depression after stroke as an alternative to medication (Laidlaw et al, 2003).

One psychological approach that has been applied to depression in stroke patients is cognitive behaviour therapy (CBT). CBT is a generic term encompassing therapies that incorporate behavioural interventions aimed at reducing dysfunctional emotions by altering behaviours and cognitive interventions which aim to reduce dysfunctional emotions by altering appraisals and thinking patterns. The cognitive components are based upon the negative appraisal of stroke, such as the feeling of failure as the individual can no longer accomplish tasks they could previously. The behavioural components concern reduced positive reinforcement resulting from physical limitations, for example by increasing activity levels and positive interactions with others and the environment. In addition to providing coping skills and techniques to improve current depressed mood, CBT can help patients prevent or alleviate future episodes of depression (Grober et al 1993).

Lincoln et al (1997) found some evidence for the effectiveness of CBT to treat depression in stroke patients in a pilot study (case series design) of 19 patients, with four showing consistent benefit and six some benefit, although nine showed no benefit. However, in a randomised controlled trial Lincoln and Flannaghan (2003) found that CBT was no more effective than an attention placebo. This raises the

question of whether CBT was not effective as the cognitive model of depression may not be applicable to stroke patients. One possible explanation for the non significant finding is that performance on the depression outcome measures could have been in part a reflection of physical recovery from the stroke rather than changes in cognitions due to therapy. This suggests that in order to evaluate psychological interventions for depression after stroke it is important to select a valid outcome measure that assesses the construct or constructs that the therapy is aiming to change. For example, as one of the aims of CBT is to reduce negative cognitions and increase positive thinking, it is important to assess whether treatment has achieved this. Therefore, research needs to establish whether depressed stroke patients experience a greater frequency of negative cognitions than those who are not depressed as predicted by the cognitive model of depression in order to demonstrate that CBT is appropriate. In order to assess this and whether CBT in stroke patients modifies cognitions a valid assessment of cognitions for stroke patients is required.

In order to investigate the cognitions of stroke patients, the Stroke Cognitions Questionnaire was revised in response to the findings of Nicholl et al (2002) and a larger set of CBT treatment notes were used to develop new items. The rationale behind the Stroke Cognitions Questionnaire Revised (SCQR) was to develop a reliable and valid measure which consisted of negative thoughts reported by stroke patients, and the nature of these thoughts is such that they may be appropriate to be addressed in CBT. The measure should also contain positive cognitions to determine whether depressed mood in stroke patients is associated is also characterised by a decrement of positive thinking. Identification of positive thoughts may also provide useful information for a therapist to facilitate positive thinking (Ingram & Wisnicki,

1988). This assessment can be used to evaluate whether the cognitive model of depression is applicable to stroke and guide future interventions. Nicholl et al (2002) found that depressed stroke patients reported more negative cognitions and less positive cognitions than those who were not depressed. This finding may be due to an over-representation of negative statements in the SCQ (twelve negative and five positive items). The revised version therefore included a more equal number of positive and negative items to. The present study also collected data on inter-rater reliability and test-retest reliability to further evaluate the reliability of the scale.

The aims of the present study were:

- To revise the Stroke Cognitions Questionnaire by removing items recommended by the authors (Nicholl et al, 2002) and to add new items following the review of a larger sample of treatment notes.
- To evaluate the construct validity and internal consistency of the revised scale in a sample of hospitalised stroke patients.
- To evaluate the test-retest and inter-rater reliability of the revised scale.

2.2 Method

2.2.1 Design

The study was a cross-sectional and correlational design.

2.2.2 Development of the Stroke Cognitions Questionnaire Revised (SCQR)

Firstly, the findings from the original study were reviewed to determine if any items should be removed from the scale. Following the recommendations of Nicholl et al (2002) item 15 from the SCQ ('I'm unable to achieve what I used to') was removed as it did not load onto either of the two factors (positive cognitions and negative cognitions) identified in the factor analysis and the low item-total correlation suggested it did not relate to the remainder of the questionnaire. This statement is more a factual reflection of the physical consequences of the stroke rather than a negative automatic thought. Nicholl et al (2002) also recommended the removal of item 8 ('I'm determined to overcome my difficulties) as it was severely skewed (skew=2.80 and 48/50 patients responded 'often' or 'sometimes') and it did not correspond to a classification of depression on the Beck Depression Inventory or the Wakefield Depression Inventory.

Statements 4, 13 and 14 were also removed from the SCQ. Item 4 – 'I feel physically tired' was not a negative cognition but a somatic item and did not meet the rationale of the revised scale. Responses to this item are likely to reflect physical improvement in the patient rather than a cognition which would be challenged in CBT. Item 13 'I have lots of people to help me' was severely skewed (skew=2.05, 45/50 patients responded 'often' or 'sometimes') and is a statement of the level of support received by the patient rather than a negative thought. Item 14 'I don't go out as much as I'd

like' was also removed as it is inappropriate for hospitalised patients and does not reflect a negative automatic thought. Responses to the item could also be a reflection of the level of physical disability. This also applies to statement 6 ('If I didn't feel so poorly I'd feel better in mood') which was considered to be vague and does not represent a negative thought and so was removed from the scale.

Statements 1 and 7 were reversed from being negative cognitions to positive cognitions as only five out of 17 statements in the original SCQ were positive and part of the rational for revising the scale was to include a more equal representation of positive items. Items 1 and 7 were chosen to be reversed as the wording of these statements allowed them to be expressed positively without changing their meaning. Statement 10 was reworded to 'I'm frustrated about not being able to do the things I want to' to make it more specific and less vague. Items 2, 3, 9, 11, 12, 16 and 17 remained unchanged as they were appropriate in the original version of the scale.

The transcripts of CBT treatment sessions and patient completed diaries from 38 depressed stroke patients were used to develop new items for the SCQR. Of the 38 patients whose treatment notes were used, 14 were from the 19 who received CBT in a pilot study evaluating the efficacy of CBT to treat depression after stroke (Lincoln et al, 1997) and 24 were from the patients in a randomised control trial evaluating CBT for depression after stroke (Lincoln & Flannaghan 2003). The treatment notes for the remaining 20 patients from both studies were unavailable for analysis. The researcher (ST) was blind as to whether patients improved or not following CBT and which of the two studies they were from. Twenty-three of the 38 patients were

women (60.53%) and the mean age was 69 years old (range 31 – 90 years). Patients received between three and 15 treatment sessions.

Ten new statements (four positive, six negative) were developed for the SCQR. These items were developed in a similar manner to the original questionnaire whereby the researcher (ST) reviewed treatment notes and diaries completed by patients and recorded statements and patient diaries verbatim in addition to underlying themes (for example, loss of confidence) which were considered to represent positive and negative cognitions. These were then used to write succinct statements for inclusion in the questionnaire. The new items reflected themes such as feelings of failure, loss of confidence, acceptance of disability and sense of achievement. Due to the varied level of detail recorded in the notes it was not appropriate to perform formal qualitative analysis.

Table 2.1 summarises the revisions made to the SCQ to produce the Stroke Cognitions Questionnaire Revised (SCQR). The SCQR can be found in Appendix 1.

Table 2.1 Revisions to the Stroke Cognitions Questionnaire

Stroke Cognitions Questionnaire	**Stroke Cognitions Questionnaire - Revised**
1. There's nothing to look forward to	Reversed **1.** *I have lots to look forward to*
2. I can't be bothered to do anything	No change **20.** I can't be bothered to do anything
3. I feel inadequate and helpless	No change **3.** I feel inadequate and helpless
4. I feel physically tired	Removed
5. I feel a burden to others	No change **6.** I feel a burden to others
6. If I didn't feel so poorly I'd feel better in mood	Removed
7. I lack motivation and interest in things I used to enjoy	Reversed **4.** *I still have motivation and interest in things I used to enjoy*
8. *I'm determined to overcome my difficulties*	Removed
9. *I feel I have a lot left to give*	No change **16.** *I feel I have a lot left to give*
10. I'm frustrated about not being able to do anything	Reworded **8.** I'm frustrated about not being able to do the things I want to
11. I dwell on what I'm unable to achieve	No change **18.** I dwell on what I'm unable to achieve
12. *I feel I'm in control of my life*	No change **13.** *I feel I'm in control of my life*
13. *I have lots of people to help me*	Removed
14. I don't go out as much as I'd like	Removed
15. I'm unable to achieve what I used to	Removed

Stroke Cognitions Questionnaire	Stroke Cognitions Questionnaire - Revised
16. *I'm optimistic about the future*	No change **7.** *I'm optimistic about the future*
17. I feel alone and unwanted	No change **14.** I feel alone and unwanted
	New item **2.** *I still get a sense of satisfaction and achievement from life*
	New item **5.** I get irritated easily
	New item **9.** I wonder what the point of living like this is
	New item **10.** *I'm accepting my limitations and disabilities*
	New item **11.** There's no point in doing things if I can't do them as well as before
	New item **12.** I'm no good at anything
	New item **15.** I feel like a failure
	New item **17.** I have lost confidence in myself
	New item **19.** *There's lots to be happy about*
	New item **21.** *I feel I am coping*

Positive items in italics

The Stroke Cognitions Questionnaire Revised (SCQR) consisted of a 21-item measure containing nine positive cognitions and 12 negative cognitions. As with the SCQ, for each item patients are required to indicate whether they have had each of the thoughts 'often', 'sometimes', 'rarely' or 'never' in the past month. Responses are scored in the same way as the SCQ on a 0-3 response scale with 0=never and 3=often for negative cognitions and scores being reversed for positive cognitions. Scores therefore range from 0-63, with a higher score corresponding to more negative cognitions. The positive subscale scores can range from 0-27 and the negative subscale between 0-36. The SCQR was administered to a sample of hospitalised stroke patients to evaluate reliability and validity.

2.2.3 Participants

Stroke patients admitted to the two stroke wards (wards F20 and F21) at Queens Medical Centre (QMC) Nottingham and the stroke ward (Beeston Ward) at Nottingham City Hospital between November 2001 and May 2002 were considered for inclusion in the study. Patients were eligible for inclusion at any time post-stroke. Patients' eligibility for recruitment was established by the research assistant (ST) attending the case conference for the wards and on the advice of ward staff.

Inclusion Criteria

Patients who met the following criteria were eligible for recruitment into the study:

- They had been diagnosed as having had a stroke as documented in their hospital medical notes.
- They were able to communication sufficiently well to understand and answer the questionnaires. This was determined on the advice of ward staff and the speech and language therapist.

- They were able to give informed consent. This was determined on the advice of ward staff.

Exclusion Criteria

Patients who met the following criteria were not recruited into the study:

- They had dementia documented in their medical notes, or dementia was suspected, as they may be unable to provide accurate responses.
- Patients who were aphasic or had communication problems preventing them from understanding the questionnaires and providing accurate responses. This was determined on the advice of ward staff and the speech and language therapist.
- If they were blind or deaf as this would preclude standardised administration of the scale.
- If they were too ill to assess. This was determined on the advice of ward staff.
- If they did not consent to participate.

2.2.4 Measures

The following details were recoded from the patients' hospital medical notes to obtain demographic information and stroke characteristics: date of birth, date of stroke, side of weakness, Bamford stroke classification and Barthel Index score. The Bamford stroke classification was explained in the literature review (Section 1.1.2) and patients were classified as TACS, PACS, POCS or LACS. The Bamford classification was included as a descriptor of the stroke characteristics of the sample.

The Barthel Index (Collin, Wade, Davies, & Horne, 1988) is a widely used measure of independence in basic activities of daily living (ADL). It is a ten item scale scored

between 0 and 20, with a higher score indicating greater independence in ADL. The Barthel Index was routinely recorded in the medical notes for the stroke wards included in this study. It was included in the present study as a measure of the level of disability.

The SCQR was completed with patients. Description and development of this scale can be found in section 2.2.2.

In addition to the SCQR the researcher also completed the Beck Depression Inventory II (BDI-II) (Beck, Steer, & Brown, 1996) with the patient. The BDI-II was included as a measure of depression severity to evaluate the concurrent validity of the SCQR and also to identify patients as depressed and not depressed to test whether depression was related to the reporting of positive and negative cognitions. Nicholl et al (2002) used the original version of the Beck Depression Inventory (Beck & Steer, 1987) to validate the SCQ. The present study used the updated version of this scale as it supersedes the previous version and was revised to concord with DSM-IV criteria for depression. The BDI-II is a 21 item self-report measure of depression. For each item the patient is required to select which one of four statements of increasing intensity best describes how they have been feeling in the past two weeks. Each item is scored between 0 and 3 with a higher score corresponding to the most intense item. Scores for the items are summed to give a total score between 0 and 63, with a higher score indicating greater depressed mood. Beck et al (1996) provided evidence for high internal consistency, test-retest reliability and discriminative validity of the BDI-II. The BDI-II has been recommended to assess mood in stroke patients (Turner-Stokes & Hassan, 2002).

2.2.5 Ethics

The study was approved by Nottingham Local Research Ethics Committee.

2.2.6 Procedure

Patients who met the inclusion criteria were approached by the researcher and invited to take part in the study. Patients were given an 'Information for Patients' sheet to read. At least 24 hours later the researcher returned to the patient to ask whether they were willing to participate in the study. Patients who agreed to take part signed a consent form. The researcher then recorded the demographic information, Bamford stroke classification and Barthel Index score from the medical notes.

The SCQR and BDI-II were administered by the researcher with the patient on the ward, either at the patient's bedside or in a quiet room. The researcher read aloud questions and responses to the patient. Assessments took between 10 and 20 minutes to complete. The order of administration of the BDI-II and SCQR was counterbalanced such that for the first patient the SCQR was administered first, for the second patient the BDI-II was administered first, and so on.

2.2.7 Inter-rater Reliability

Inter rater reliability was evaluated for the first twenty patients recruited to the study. Two researchers were present when the SCQR was administered to the patient. Administration by the researchers was counterbalanced such that for the first patient researcher 1 administered the SCQR and researcher 2 observed, for the second patient researcher 2 administered the questionnaire and researcher 1 observed, and so on. Both researchers recorded the patient's response to each item and each researcher was blind to the other's answers.

2.2.8 Test-retest reliability

Test-retest reliability was also evaluated for the first twenty patients recruited to the study. For the first 20 patients the researcher revisited the patient one week after the first assessment and completed the SCQR again with the patient.

2.3 Results

2.3.1 Patient characteristics

During the time frame of the study 111 patients were identified on the stroke wards and considered for inclusion in the study. Of the 111 patients, 42 (37.84%) did not meet the inclusion criteria: 20 (18.02%) were aphasic or had communication problems preventing them from being able to complete the questionnaires, 20 (18.02%) were too ill to assess and two patients (1.80%) had dementia documented in their medical notes. Ten (9.01%) of the 111 patients were discharged from hospital before the researcher could invite them to take part or were unavailable to be assessed. Therefore, 59 patients were approached by the researcher and invited to take part of the study. Of these 59 patients, nine (15.25%) did not consent to take part and 50 consented to participate (84.75%). Therefore, 50 patients were assessed in the present study, 31 were recruited from QMC and 19 from Nottingham City Hospital.

Of the 50 patients, 19 were women. Patients were between 40 and 90 years old with a mean age of 71.9 years (SD=11.75). Patients were between 10 and 135 days post-stroke when they were assessed, mean time post-stroke was 47.80 days (SD=35.81). The SCQR and BDI-II were only slightly positively skewed, with skew values of .401 and 1.460 respectively. Both the SCQR (p=.069) and the BDI-II (p=.083) did not significantly differ from the normal distribution using the Shapiro-Wilk test, therefore parametric statistics were used to analyse the data.

2.3.2 Stroke Characteristics

The Bamford stroke classification is summarised in Table 2.2. PACS was the most common stroke subtype and POCS the least common. Thirty eight patients had a left sided weakness, 10 had a right-sided weakness and for two patients no side of

weakness was recorded in hospital medical notes. Barthel scores ranged between 2 and 20 with a mean of 11.18 (SD=5.2).

Table 2.2 Frequency of Bamford stroke classification

Bamford Stroke Classification	n (%)
LACS	12 (24%)
PACS	22 (44%)
POCS	6 (12%)
TACS	10 (20%)

2.3.3 Relationships between SCQR scores and demographic information

Person's correlations showed that there was no significant correlation between age and SCQR scores (r=.237, p=.102) and between age and BDI-II scores (r=.131, p=.369). Pearson's correlations were two-tailed for this analysis and all other correlations conducted in this thesis. Two-tailed tests are most common and are recommended as the researcher may not know what the direction of the data will look like and trends can be opposite of that predicted by the researcher (Howell, 1997). One-tailed tests are sometimes appropriate, such as when only one direction is biologically meaningful or there is good evidence that an association will not occur in one direction (Hulley et al, 2001). However, as throughout this thesis it would not have been impossible for correlations to occur in either direction, two-tailed tests were considered appropriate.

There was no significant difference between the scores on the SCQR for men (mean=20.68, SD=12.55) and women (mean=17.37, SD=13.81) (t_{48}=.871, p=.388). Similarly, BDI-II scores did not significantly differ between men (mean=13.58,

SD=9.79) and women (mean=11.32, SD=7.01). There was a positive correlation between time since stroke and SCQR scores (r_s=.323, p<.031), such that patients reported more negative cognitions and less positive cognitions the as time after stroke increased. There was also a significant positive correlation between time since stroke and BDI-II scores (r=.347, p=.019) such that mood was lower as time after stroke increased.

2.3.4 Relationship between SCQR scores and stroke characteristics

There was no significant difference in SCQR scores between patients who had a right sided weakness and those who had a left sided weakness (t_{48}=-.409, p=.684). Similarly, BDI-II scores were not significantly different between patients with a right sided weakness and a left sided weakness (t_{48}=-1.127, p=.266). There was a significant negative correlation between Barthel scores and SCQR scores (r=-.467, p=.005) and between Barthel scores and BDI-II scores (r=-.519, p=.002), such that an increase in independence in ADL was associated with lower levels of depression and less depression related cognitions. One-way ANOVAs showed that there was no significant difference between Bamford stroke classification and SCQR scores ($F_{3,47}$=.851, p=.471) and between Bamford stroke classification and BDI-II scores ($F_{3,47}$=.236, p=.871).

2.3.5 Relationship between BDI-II and SCQR scores

Descriptive statistics for BDI-II and SCQR are shown in Table 2.3. The total scores on both the BDI-II and SCQR were low given the possible range of scores, although the standard deviation of the SCQR total score was large, indicating a wide variance in scores.

Table 2.3 Descriptive Statistics for BDI-II and SCQR

	Mean	SD	Range
BDI-II			
Total	12.72	8.86	0-49
Somatic-affective subscale	9.00	8.42	0-30
Cognitive subscale	4.00	5.58	0-19
SCQR			
Total	19.49	13.15	0-48
Positive Cognitions	6.96	6.21	0-23
Negative Cognitions	12.53	8.98	0-33

Positive cognitions – higher score indicates less positive cognitions
SD=standard deviation

Pearson's correlations were calculated between SCQR and BDI-II total and subscale scores. These are summarised in Table 2.4. BDI-II cognitive and somatic-affective subscale totals were calculated according to Steer et al (1999).

Table 2.4 Correlations between SCQR and BDI-II total and subscale scores.

	BDI-II total		BDI-II cognitive subscale		BDI-II somatic affective subscale	
	r	p	r	p	r	p
SCQR total	0.812	<.001***	0.800	<.001***	0.752	<.001***
SCQR positive cognitions	0.641	<.001***	0.540	<.001***	0.582	<.001***
SCQR negative cognitions	0.747	<.001***	0.711	<.001***	0.790	<.001***

r Pearson's correlation; p probability; *** $p \leq .001$

There were significant correlations between the SCQR total, positive cognitions and negative cognitions and the BDI-II total and subscale scores. Therefore lower mood was associated with more frequent negative cognitions and less frequent positive cognitions. This demonstrates strong concordance between subscale scores (somatic-affective, cognitive, positive and negative cognitions) and questionnaire score totals and concurrent validity of the SCQR is supported by the significant correlations found between the SCQR and BDI-II total and subscale scores.

2.3.6 Partial Correlations

Time since stroke and Barthel scores were found to be correlated with both BDI-II scores and SCQR scores, therefore it is possible that the correlations between BDI-II and SCQR could be attributable to the fact that both scales were correlated with these factors. To test this, partial correlations were performed between BDI-II and SCQR total and subscale scores firstly controlling for time since stroke and secondly controlling for Barthel Index scores. All correlations remained significant when time since stroke and Barthel scores were controlled for ($r=0.476$-0.948, $p<0.01$-$p<0.001$). Therefore, the relationship between the SCQR and BDI-II total and subscale scores cannot be accounted for by their relationship with time since stroke and Barthel scores.

2.3.7 Internal Reliability of the SCQR

Cronbach's alpha for the SCQR was 0.91 and Guttman's split half was 0.94 demonstrating that the scale had high internal reliability; therefore each item was related to all of the other items in the scale. Item total correlations and alpha values if items were deleted from the scale are summarised in Table 2.5. Item-total correlations ranged from 0.28-0.78 and these correlations were lower for positive items. No alpha values were increased through the deletion of items from the

questionnaire. There was a significant correlation between positive cognitions and the SCQR total score ($r=.774$, $p<.001$) and between negative cognitions and the SCQR total score ($r=.881$, $p<.001$). Correlations between items on the SCQR on the correlation matrix range from –0.08 to 0.75 suggesting that there was no multicollinearity between items.

2.3.8 Item response characteristics

A four-point response scale was employed for the SCQR items as this prevented people from selecting a 'neutral' option. Also by wording some statements positively and some negatively this prevented a response set whereby the patient gives the same response for every item. Items were dichotomised into often/sometimes and rarely/never in order to calculate the probability of endorsing each item. The proportion of people endorsing each item ranged between 0.05 and 0.88, indicating that for each item a majority of people were not responding with the same alternative (Streiner & Norman 2001).

Table 2.5 Item-total correlations and Alpha values for SCQR

Item number	Item-total correlation	Alpha if item deleted
1	0.54	0.90
2	0.58	0.90
3	0.43	0.91
4	0.50	0.90
5	0.40	0.91
6	0.53	0.60
7	0.50	0.90
8	0.58	0.90
9	0.66	0.90
10	0.28	0.91
11	0.49	0.90
12	0.57	0.90
13	0.62	0.90
14	0.64	0.90
15	0.78	0.90
16	0.35	0.91
17	0.67	0.90
18	0.50	0.90
19	0.65	0.90
20	0.49	0.90
21	0.59	0.90

2.3.9 Relationship between the SCQR and depression classification

A cut-off of 14 on the BDI-II was used to classify patients as depressed, as recommended by the manual (Beck et al, 1996). Twenty patients (40%) were classified as depressed on the BDI-II. Comparisons were made between depressed and non-depressed patients on the SCQR scores to evaluate whether there was a significant difference in the amount of positive and negative cognitions they reported. Independent samples t-tests tests showed that depressed patients scored significantly higher than non-depressed patients on the SCQR (t_{48}=-6.488, p<.001). Depressed patients were also found to report significantly more negative cognitions (t_{48}=-6.421, p<.001) and significantly less positive cognitions (t_{48}-3.533, p<.001) than non-depressed patients.

Patients' responses to individual items on the SCQR were examined to see whether responses differed between patients classified as depressed on the BDI-II and those not classified as depressed. The SCQR items were recoded such that a response of 'rarely' or 'never' scored 0 and 'sometimes' or 'often' scored 1 to indicate the presence or absence of each cognition. Chi squared tests were performed on the data and Fisher's Exact Test was used when the expected frequency was <5.

For 11 out of the 12 negative cognition items on the SCQR, depressed patients were significantly more likely to report the negative cognition often or sometimes than non depressed patients. Items 5, 9, 15 and 17 were significant at p<.001, items 3, 6 and 20 were significant at p<.01 and the remaining items at p<.05. Responses to item 11 'There's no point in doing things if I can't do them as well as before' did not significantly differ between patients classified as depressed and not depressed (p=.279).

For five out of the nine positive cognition items on the SCQR (items 1, 4, 7, 13 and 19), patients who were not depressed on the BDI-II were significantly more likely to report experiencing these positive cognitions often or sometimes compared to patients depressed on the BDI-II. Item 7 was significant at $p<.001$ and the remaining items at $p<.05$. Responses to items 2, 10, 16 and 21 did not significantly differ between depressed and non depressed patients ($p=.058$-$p=.635$). Therefore the most important difference between depressed and non depressed patients was the preponderance of negative cognitions rather than an absence of positive cognitions.

2.3.10 Exploratory Factor Analysis of the SCQR

Exploratory factor analysis was performed on the SCQR to determine the number of factors underlying the 21 statements which were designed to assess the frequency with which patients experienced positive and negative cognitions. This would ascertain whether the questionnaire exhibited a two-factor structure of positive and negative cognitions as was intended when it was developed.

Pre-analysis checks

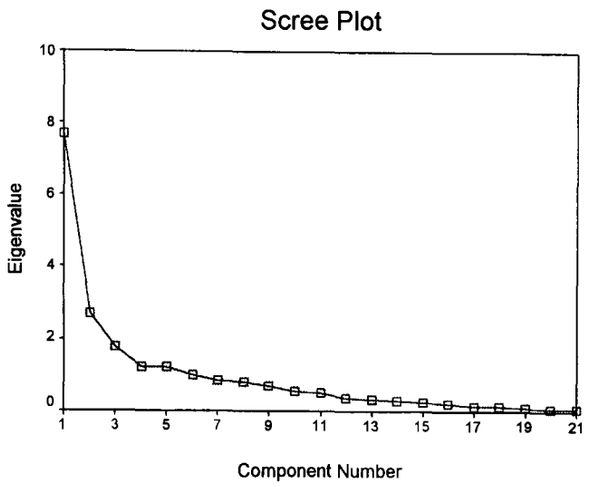
All 50 patients provided completed data on the SCQR and were included in the analysis. This provided a subjects to variables ratio of 2.38:1 which exceeds the minimum recommendation of 2:1 (Ferguson & Cox, 1993). The ratio of variables to expected factors was 10.5:1 and of subjects to expected factors 25:2. It has been suggested that if all communalities are >0.6 then smaller samples (less than 100) may be adequate (Field, 2000). Prior to extraction all communalities were equal to 1 and after extraction all communalities were >0.6 (0.600-0.836).

The skew of the items ranged from –1.151 to 1.851 and kurtosis between –1.67 and 2.87 with only two items having a kurtosis >2. As the percentage of variables affected by skew or kurtosis was <25%, as recommended by Ferguson and Cox (1993), no items were removed before performing the analysis. The Kaiser-Meyer-Olkin (KMO) test of sampling adequacy for the item-total correlations was 0.731; this is considered 'good' and exceeded the minimum recommended value of 0.5 (Field, 2000). The Bartlett test of sphericity was significant (χ^2=608.60, p<0.001) indicating that there are some relationships between the variables in the data. The correlations in the off-diagonals of the correlation matrix were <0.8, implying that there was no multicollinearity in the questionnaire items. Each item on the diagonal of the anti-image correlation matrix was >0.5 (range 0.502-0.895). The data were therefore suitable for exploratory factor analysis which was performed on the full 21-item scale.

Factor Extraction

The K1 method (Eigenvalues >1) would have extracted five factors (Eigenvalues 7.68, 2.67, 1.76, 1.22 and 1.20), accounting for 73.98% of the variance. However, as this method of extraction is known to over-factor and is less accurate when there are less than 30 variables (Field, 2000) a scree plot was constructed. The scree plot is shown in Figure 2.1

Figure 2.1. Scree plot



The scree plot indicates that there is a break in the curve between components 2 and 3 and between components 3 and 4. However, the third component only added a small amount to the total variance (5%). Two factors were extracted based on the scree plot and apriori expectation of a two factor structure of positive and negative cognitions. These two factors these accounted for 57.71% of the total variance.

2.3.11 Factor Rotation

Two factors were extracted using Principal Components Analysis. The solution was rotated using orthogonal (Varimax) rotation as correlation was not expected between the factors and this converged in three iterations. Rotation was used to show more clearly which variables are related to which factors, as this procedure maximises the loading of the variable on one factor and minimised the loading on the remaining factors. The rotated factor matrix is displayed in Table 2.6.

Table 2.6. Rotated Factor Matrix

Statement	Factor 1	Factor 2
15	**0.752**	0.397
3	**0.744**	0.138
18	**0.714**	0.058
9	**0.696**	0.290
17	**0.695**	0.274
12	**0.684**	0.170
8	**0.666**	0.142
6	**0.661**	0.113
20	**0.641**	0.081
14	**0.600**	0.377
11	**0.550**	0.228
5	**0.420**	0.216
1	0.057	***0.810***
19	0.231	***0.788***
21	0.178	***0.767***
2	0.198	***0.734***
13	0.263	***0.700***
7	0.176	***0.673***
4	0.228	***0.615***
16	0.037	***0.541***
10	0.055	***0.453***

Positive items in italics

A minimum loading of 0.4 is recommended as the threshold at which an item is considered to load onto a factor (Field, 2000). Using this criteria, items 3, 5, 6, 8, 9, 11, 12, 14, 15, 17, 18, and 20 loaded onto factor one and items 1, 2, 4, 7, 10, 13, 16, 19 and 21 loaded onto factor 2. The rotated factor matrix was inspected for crossloadings (when the difference between the loadings of an item on the two factors is <0.2) and no crossloadings were evident.

The items which loaded highest on factor 1 were the 12 negative cognitions and the nine items which load highest onto factor 2 were positive cognitions.

2.3.12 Inter-Rater Reliability

Of the 20 patients on whom inter-rater reliability data was collected, 11 were men (55%). The mean age of these patients was 71.2 years (SD=10.25) and they were assessed a mean of 32.5 days after stroke (SD=31.02).

Kappa values were calculated for each of the items on the SCQR and are shown in Table 2.7. As shown in the table, excellent agreement was found for all 21 items, with Kappa values less than one for only four of the items (excellent classified as $\geq$ 0.75) (Fleiss, 1981). Pearson's correlation of SCQR total scores for the two raters was 0.999 ($p<.001$).

Table 2.7 Kappa values for items on the SCQR

Item	Kappa	Agreement
1	1	Excellent
2	1	Excellent
3	1	Excellent
4	0.89	Excellent
5	0.93	Excellent
6	1	Excellent
7	1	Excellent
8	1	Excellent
9	1	Excellent
10	1	Excellent
11	1	Excellent
12	1	Excellent
13	1	Excellent
14	1	Excellent
15	0.92	Excellent
16	0.92	Excellent
17	1	Excellent
18	1	Excellent
19	1	Excellent
20	1	Excellent
21	1	Excellent

2.3.13 Test retest reliability

Test-retest reliability was conducted using the first 20 patients, therefore the demographic characteristics for this group of patients is the same as reported for inter-rater reliability. Table 2.8 shows the descriptive statistics for the SCQR scores at Time 1 and Time 2 for the 20 patients. The scores between patients at Time 1 and Time 2 were compared using paired samples t-tests and no significant difference was found between the SCQR total scores and positive and negative subscale scores at Time 1 and Time 2.

Table 2.8. Descriptive statistics of SCQR at Time 1 and Time for test-retest reliability

	Time 1		**Time 2**		**Comparison**
	Mean	SD	Mean	**SD**	**p**
SCQR total score	21.45	11.00	21.95	12.94	.769
SCQR positive cognitions	7.35	5.10	7.30	4.68	.900
SCQR negative cognitions	14.00	9.15	14.70	9.90	.652

Pearson's correlations showed that scores at Time 1 and Time 2 were significantly correlated for the SCQR total score ($r=0.816$, $p<.001$), positive cognitions ($r=0.718$, $p<.001$) and negative cognitions ($r=0.745$, $p<.001$). Bland and Altman (1986, 1995) argued that a significant correlation between scores at two assessment points does not mean that there is agreement as there will be perfect correlation if the points lie along any straight line, even if scores are not the same at both measurement points.

Therefore, Bland-Altman plots were constructed for the SCQR total and positive and negative cognitions subscales, whereby the difference between the scores at Time 1 and Time 2 is plotted against the mean score for Time 1 and Time 2. The mean and 95% confidence interval for the difference between Time 1 and Time 2 assessments are also plotted on the graphs. These are shown in Figures 2.2, 2.3 and 2.4. All but one of the patients was inside of the 95% confidence interval of the difference between the two assessment points for the SCQR total and subscale scores. This indicates very good agreement between the two time points as 95% of differences are expected to be within two standard deviations (Bland & Altman, 1986).

Figure 2.2. Bland Altman plot of SCQR total scores

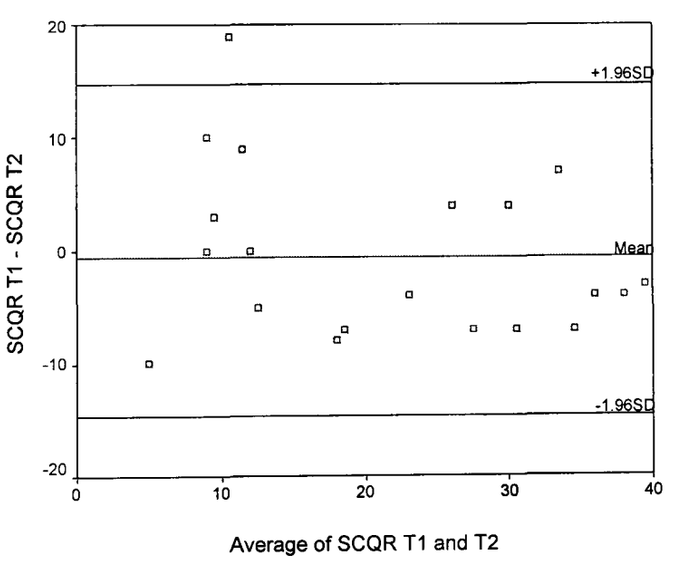


Figure 2.3. Bland Altman plot of SCQR positive cognitions

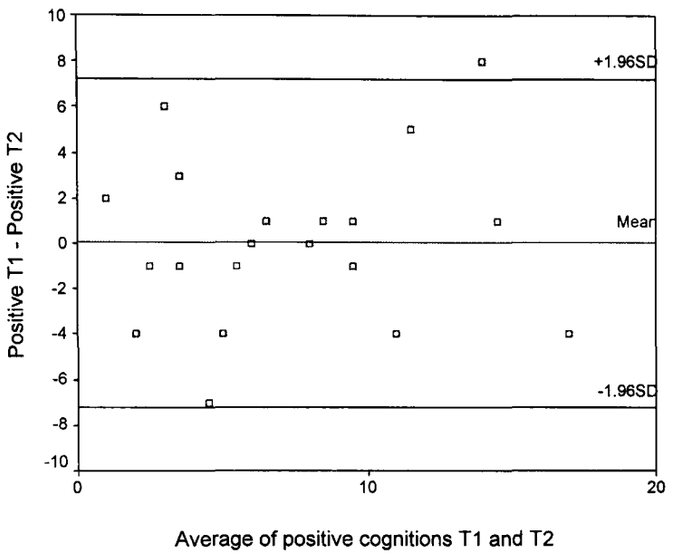
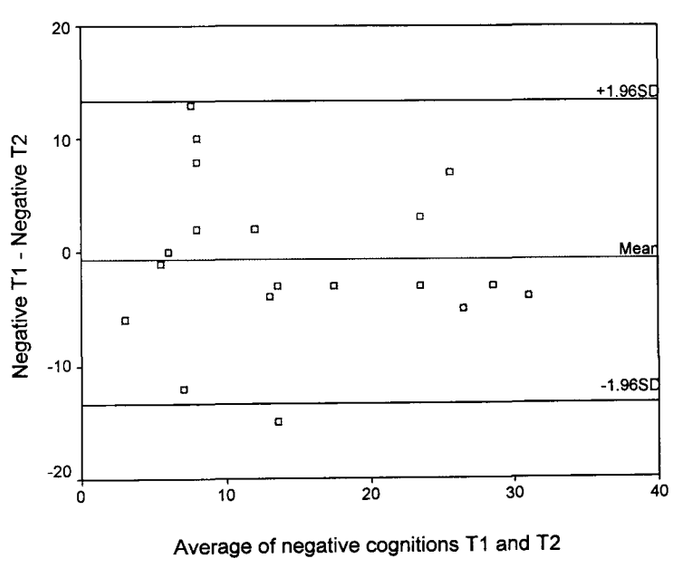


Figure 2.4. Bland Altman plot of SCQR negative cognitions



2.4 Discussion

2.4.1 Reliability and Validity of SCQR

The SCQR was shown to have high internal consistency with Cronbach's alpha and Guttman's split half values suggesting that the scale contains homogeneous items. The negative items correlated higher with the total scale score. Alpha values did not increase through removing any of the items and the correlation matrix did not show any evidence of singularity or multicollinearity in the scale. These findings suggest that based on the data collected on the scale so far in a sample of hospitalised stroke patients no items should be removed from the scale.

The internal consistency of the SCQR was comparable to the original version of the scale. The revised scale showed a clear two factor structure whereas the original scale found a three factor structure in which two items loaded onto a third factor. The two factors of positive and negative cognitions accounted for just over half of the variance in the scores and this did not largely increase if more factors were added. Also, the items in the SCQR were better at discriminating between depressed and non depressed patients than the items in the SCQ. Therefore, the modifications that have been made to the scale have improved the discriminant validity of the scale and provided evidence for a two factor structure of the scale with positive and negative cognitions subscales. The findings support the use of the SCQR in favour of the SCQ as it was developed using treatment notes from a larger sample of patients than the original version and items performing poorly in the SCQ were removed.

The SCQR demonstrated concurrent validity as the total and subscale scores correlated significantly with the BDI-II. Partial correlations to control for time since

stroke and Barthel scores, which were found to correlate with the SCQR and BDI-II, showed that the two scales remained significantly correlated. A higher score on the SCQR, indicative of a high frequency of negative cognitions and low frequency of positive cognitions, was therefore associated with lower mood indicated by higher scores on the BDI-II. The SCQR correlated with both the cognitive and somatic-affective items on the BDI-II, indicating that the cognitions items were associated both with the cognitive and the somatic symptoms of depression.

Using the recommended cut-off on the BDI-II 40% of patients were classified as depressed, this is within the range of prevalence estimates for hospitalised stroke patients reported in the literature review. Depressed patients reported significantly more negative cognitions and significantly less positive cognitions than patients who were not depressed. This provides evidence for construct validity of the SCQR as the predominance of negative thoughts in depressed patients is predicted by cognitive model of depression. It is possible that the recruitment method used induced bias in the sample in the present study. As patients were required to consent to take part it is possible that those patients who did not consent had lower mood than those who did participate, as low motivation and interest are characteristics of depression.

These findings were further supported by assessing the relationship between individual items on the SCQR and depression classification. Depressed patients reported having significantly more negative cognitions across all of the negative cognitions items. The positive items on the SCQR did not differentiate the depressed and non-depressed patients as well as the negative items. This suggests that the most important difference between depressed and non depressed patients was the presence

of negative cognitions and to a lesser extent the absence or decrement of positive cognitions. Five out of nine of the positive cognitions were reported more frequently in those patients not depressed on the BDI-II. This replicates the findings of the Nicholl et al (2002) but also extends the findings as the SCQR contained more even proportions of positive and negative cognitions than the SCQ. Therefore, the findings of the relationship between positive and negative cognitions and depression caseness and severity found in the original study cannot be attributed to the preponderance of negative items in the SCQ.

The SCQR was found to have excellent inter-rater reliability on all items, this demonstrates the researchers showed high concordance in recording the patients' responses in the appropriate category. This may be because the patient is required to select from four response options rather than providing a free response. The scale is therefore suitable for use by different administrators. Test retest reliability over a one week interval was also very good. This shows that there was consistency in patients' responses over time and suggests the scale is assessing stable responses.

The results from the present study provide support for the applicability of the cognitive model of depression to stroke patients and this suggests that therapies for depression that are based on this model, such as CBT, can be applied to stroke. The findings also support the notion that depression in stroke is not qualitatively different to depression in psychiatric patients as the same pattern of cognitions was found (Nicholl et al, 2002). The negativity hypothesis (Haaga et al, 1991) was supported by the finding that patients classified as depressed reported significantly more negative cognitions than non depressed patients. Furthermore, the exclusivity hypothesis

(Haaga et al, 1991) was also supported by the finding that depressed patients also reported significantly less positive cognitions than those who were not depressed, although this was not found for all positive items. This suggests that in stroke patients the most important distinction between depressed and non depressed patients is the presence of negative cognitions, and such cognitions are amenable to CBT. The findings support a previous study with stroke patients that found a trend for depressed patients to report more negative cognitions than those who were not depressed (Noble, 1993). Previous studies that investigated the cognitions of medical patients used measures of cognitions that were developed and validated on younger samples of psychiatric patients, while the present study used a measure which contained cognitions relevant to stroke patients. The SCQR needs to be used in patients discharged from hospital and living in the community to explore the cognitive model of depression later after stroke when recovery has plateaued and patients are having to adjust to life post-stroke, as SCQR scores were correlated with time since stroke in the present study.

In summary, the present study has demonstrated the internal and inter-rater reliability and concurrent validity of the SCQR. The SCQR was shown to be suitable for use with hospitalised stroke patients. However, as the treatment notes from which the items were generated came from stroke patients living in the community the scale requires validation in patients who have been discharged from hospital. Also, the SCQR correlated with the Barthel Index, demonstrating that dependence in ADL was related to reporting depression related cognitions. The SCQR would need to be tested in stroke patients who were later post-stroke and were less disabled than the sample in the present study to evaluate whether cognitions are related to level of disability

and time post-stroke. The present study has extended the findings of Nicholl et al (2002) as improvements were made on the original version and inter-rater and test re-test reliability was obtained. Furthermore, concurrent validity was obtained using the BDI-II as opposed to the BDI which is in accordance with DSM-IV criteria for depression. The BDI-II was used to classify patients as depressed but this is not equivalent to a clinical diagnosis of depression. A psychiatric interview is considered the 'gold standard' method to identify depression and the findings of the present study would need to be replicated using this method in order to conclude that the results apply to a clinical diagnosis of depression.

2.4.2 Application of the SCQR

The SCQR and BDI-II were highly correlated. This raises the question of why a new measure was developed. The frequency of negative and positive cognitions were correlated with mood as was expected, however the SCQR was constructed with the rationale of designing a scale to assess cognitions which would have content validity in stroke patients and which may be addressed in CBT. The BDI-II contains somatic items which may in part be a reflection of the physical condition of the patient and changes in scores on somatic items may reflect physical recovery rather than improvement in mood.

A strength of the SCQR is that it was developed using CBT treatment notes of depressed stroke patients and they may therefore be more specific to the experiences of stroke patients than a cognitions scale developed for healthy, younger individuals. In contrast to the BDI-II and most cognitions scales, the SCQR also contains positive cognitions. This provides a scale which can be used to further investigate the both the

positive and negative cognitions of stroke patients and the applicability of the cognitive model of depression in stroke populations.

One recommended application of the SCQR is to screen stroke patients to identify those who report frequently experiencing negative cognitions (which have been found to correlate with mood) and may therefore be appropriate to be referred for CBT to treat depression. For example, item 12: 'I'm no good at anything' could be challenged in therapy by examining the evidence for and against this statement. The results would provide the therapist with a basis on which to begin therapy as it highlights the negative thoughts which can be addressed in treatment. The inclusion of positive items can indicate to the therapist any positive cognitions which the patient reports, these may be used to challenge negative cognitions. The SCQR could potentially provide a useful measure to monitor the effectiveness of CBT, as therapy endeavours to reduce the experience of negative automatic thoughts and increase positive adaptive thinking. The SCQR may be a more accurate indicator of progress in therapy than the BDI-II as it does not contain somatic items which may change irrespective of a change in cognitions. However, the SCQR was correlated with Barthel scores. In order to demonstrate that changes in cognitions are independent of physical recovery the two scales would need to be administered over several time points. Future studies should evaluate whether the SCQR is sensitive to changes in cognitions in CBT before it can be recommended as a measure to monitor the effectiveness of CBT.

The BDI was used to classify patients as depressed. This is a self-report measure rather than a psychiatric interview which is considered the gold standard for the

diagnosis of depression, although it has been used in previous stroke studies. Self-report measures of depression are known to have high sensitivity but low specificity in stroke (Lincoln et al, 2003). It would be informative for future research to replicate the findings of the present study using a psychiatric interview. A limitation of the SCQR is that it is not appropriate for aphasic patients as it requires intact communication skills to understand and provide responses to the items. This means that the findings regarding the patterns of cognitions in relationship to depression can only be applied to patients who are not aphasic as the cognitions of patients with aphasia have not been assessed. It would be interesting to evaluate whether the cognitions scale also concords with observer rated measures of mood that are used in patients who are aphasic.

The method of generating new items for the revised scale may be criticised as this was conducted by a single researcher which may have introduced bias, although the researcher was blind to whether the patient's mood improved following CBT. The level of detail recorded in the treatment notes varied across patients and there was insufficient detail to conduct formal qualitative analysis on these to identify cognitions for the scale.

2.4.3 Conclusion

In conclusion, the findings from this study support the modifications that were made to the SCQ. The present study has developed a measure of cognitions which are of relevance to stroke patients that can be used in future studies. It cannot be concluded that the cognitions items are specific to stroke, as the scale has only be used with stroke patients. The SCQR would need to be tested in other populations, such as the elderly or other physical disabilities, in order to explore whether the items are

specific to stroke patients. Also, medical comorbidities were not recorded for the sample and it is possible that these could have influences responses. Depressed stroke patients were found to report significantly more negative cognitions and significantly less positive cognitions than non-depressed stroke patients. This provides evidence for Beck's cognitive model of depression, specifically the presence of negative automatic thoughts in depression, in hospitalised stroke patients and suggests that therapies developed from this approach can be validly applied to stroke.

3 CHAPTER 3 - FACTORS RELATING TO DEPRESSION AFTER STROKE

3.1 Introduction

A stroke can cause major disruptions to a person's life, including changes in health status, occupation, social role and independence (Whyte & Mulsant, 2002). As considered in the literature review, a stroke can also be associated with a range of emotional changes. Depression is considered to be the most common neuropsychiatric consequence of stroke (Robinson, 1997), and failure to recognise and treat depression may be an important unmet need of stroke survivors (Feibel, Berk, & Joynt, 1979). Estimates of the prevalence of distress after stroke range from 25%-79% (Kneebone & Dunmore, 2000), with the variability in estimates due to the heterogeneity in methods used such as timing of assessment, screening measures and patient selection criteria. The review of the literature has shown that despite the variance in estimates across studies, emotional distress is common following stroke. Emotional distress warrants the attention of researchers as it can result in an increased use of health services and longer hospitalisation if unrecognised and untreated (Cushman, 1988). Distress in stroke survivors can be a barrier to rehabilitation and it has been found to have an independent negative effect on the long-term recovery of physical and cognitive functions (Morris, Raphael & Robinson, 1992). Distress also has a negative impact on quality of life (Jaracz, Jaracz, Kozubski & Rybakowski 2002), and is associated with increased mortality up to two years after stroke (House, Knapp, Bamford & Vail, 2001).

There is widespread agreement that early recognition and active management of distress after stroke is desirable (Turner-Stokes & Hassan, 2002). However, current therapeutic approaches are constrained by our incomplete knowledge of what factors

cause stroke patients to become distressed. Identification of the factors that are associated with distress after stroke will inform the development of appropriate therapies to address the risk factors for distress following stroke. It was found from literature review that a range of factors have been purported to be related to distress. Robinson, Kubos, Starr, Rao and Price (1984) proposed that a biological mechanism causes depression after stroke and they reported an association between left hemisphere damage, particularly left anterior lesions, and depression. However, as identified by House (1987b), the method of lesion localisation was the distance of the anterior and posterior borders of the lesion from the frontal pole, and this does not map onto functional and anatomical classifications. The consensus from the literature was that there was not sufficient evidence to support the lesion location hypothesis. Further, reviews (Carson et al., 2000; Singh et al, 1998) have found no conclusive evidence for a relationship between lesion location and distress after stroke. Studies have also investigated whether there is a relationship between the severity of disability and distress. Findings regarding this relationship have been mixed. About two thirds of the studies considered in the literature review of this thesis found some evidence that the severity of disability was related to distress, although this factor did not account for a large amount of variance in distress scores. Also, the level of disability that was assessed was predominantly basic activities of daily living (ADL) and studies have not widely considered extended ADL as an index of disability in relation to distress.

Inconclusive findings regarding the importance of lesion location and severity of disability have led other researchers to propose a psychosocial aetiology of distress (Gainotti et al, 1999). Illness representations that patients develop may be relevant

such as locus of control. For example, the perception of having little control over one's recovery (i.e. an external locus of control) has been linked to feelings of hopelessness (Sinyor et al, 1986). Morrison, Johnston and MacWalter (2000) found that a low internal locus of control one month after stroke was associated with depression outcome at six months, although this was not predictive. It is possible that the direction of causation between locus of control and depression is in the opposite direction to that predicted, namely that in fact depression affects locus of control. For example, the learned helplessness model (Seligman, 1975) proposed that individuals perceive events as uncontrollable and so depression may affect locus of control leading to it becoming more external. Alternatively, the cognitive model (Beck, 1976) proposed that depressive cognitions were characterised by negative thoughts about the self and self blame. It follows from this model that depression would affect locus of control leading to becoming more internal. These contradictory predictions, termed a 'depressive paradox' were considered by Benassi et al (1988) and a meta-analysis found consistent evidence that externality of locus of control was correlated with depression. However, this meta-analysis did not consider the direction of association. This would require a longitudinal design in which depression and locus of control were measured concurrently at more than one time point. The nature of the psychological and social factors that predispose stroke patients to developing depression has been neglected by research (House, 1987b). This suggests that future studies should explore psychosocial factors that may be related to distress.

Data were available from a treatment study of depression after stroke which could be used to explore factors related to depression, in order to inform the main study of this thesis. The present study conducted secondary analysis of data from a randomised

controlled trial of cognitive behavioural psychotherapy (CBT) to treat depression following stroke (Lincoln & Flannaghan, 2003). Lincoln and Flannaghan (2003) randomly allocated 123 depressed stroke patients who were identified between one and six months after stroke to receive CBT, an attention placebo or no intervention. Patients were reassessed at three months and six months after randomisation. CBT was found not to be effective as measured on the Beck Depression Inventory and the Wakefield Depression Inventory. The aim of the present study was to examine whether factors measured at recruitment, when patients were identified as depressed, predicted the severity of their depression at the time and whether they predicted whether patients remained depressed six months later. Factors considered included recovery locus of control in order to establish whether previous findings associating locus of control with distress are replicated, and whether this factor is relevant to include in the main study of this thesis. The present study will further our understanding of the factors associated with depression severity and also to predict which patients are at risk of not recovering from depression. The findings from the study will also be used to guide the main study in the thesis.

3.2 Method

The overall method for patient selection into the CBT trial are described in the original paper (Lincoln & Flannaghan, 2003) and so will be summarised here.

3.2.1 Design

The original study was a randomised controlled trial design.

3.2.2 Participants

Patients were identified from a Nottingham stroke register. Patients who were blind, deaf, had severe communication problems, did not speak English, or had dementia

documented in their medical notes were excluded. Also, Patients who scored <10 out of 20 on the Barthel Index (BI), as measure of independence in basic ADL, were excluded as they may have had difficulty with the behavioural components of CBT.

3.2.3 Assessments

At all three assessment points (baseline and three and six months after randomisation) patients completed the following scales:

- Beck Depression Inventory (BDI) (Beck & Steer, 1987) as a measure of mood. The BDI is scored between 0-63, with a higher score indicating lower mood. The BDI was chosen by Lincoln and Flannaghan (2003) as the main measure of mood, which would be sensitive to the effects of CBT.
- Wakefield Depression Inventory (WDI) (Snaith, Ahmed, Mehta, & Hamilton, 1971) was also included as a measure of mood as it has been used in other stroke studies and will enable comparisons with the literature. The WDI is scored between 0-36, a higher score indicating lower mood.
- Barthel Index (BI) (Collin et al, 1988) as an assessment of basic ADL that is widely used in stroke. This is scored between 0-20, with a higher score indicating greater independence in self-care.
- Extended Activities of Daily Living Scale (EADL) (Nouri & Lincoln, 1987) as an assessment of independence in instrumental activities of daily living developed for use with stroke patients. Contains mobility, kitchen, domestic and leisure subscales. The EADL is scored between 0-66, a higher score indicates greater independence.
- Sheffield Screening Test for Acquired Language Disorders (SST) (Syder, Body, Parker, & Boddy, 1993) to assess communication problems, containing

subscales of receptive and expressive communication. Performance is scored between 0-20, a lower score indicates greater communication impairment.

- Recovery Locus of Control Scale (RLOC) (Partridge & Johnston, 1989) as a measure of the extent to which patients perceive they have control over their recovery. The RLOC is scored between 9-45, a higher score is indicative of a more internal locus of control. The RLOC is discussed in detail in section 4.2.9.1 (page 203).
- General Health Quesitionnaire-28 (GHQ-28) (Goldberg & Williams, 1988) as a measure of general psychiatric morbidity. Each item is scored between 0-3, giving a total score between 0-84, with a higher score indicating lower mood.

Data was also collected on age, gender and side of weakness.

3.2.4 Procedure

Patients were identified from a Nottingham stroke register and at one month post-stroke were invited by letter to complete and return the Beck Depression Inventory (BDI) (Beck & Steer, 1987) and the Wakefield Depression Inventory (WDI) (Snaith et al, 1971). These are two well established measures of mood. Patients were considered to be depressed if they scored >10 on the BDI or >18 on the WDI. Patients who did not complete the BDI and WDI at one month, were not depressed, or were too disabled were contacted again at three months after stroke using the same procedure, and were recruited to the study if they met the inclusion criteria at this point. Those who were not included at three months were reviewed again at six months after stroke using the same recruitment procedure, and were recruited at this point if they met the inclusion criteria. Therefore, baseline data is from patients identified as depressed at one month, three months or six months after stroke.

Patients were randomised to receive no intervention, an attention placebo group or a cognitive behavioural psychotherapy from a psychologist. Outcome assessments were completed at three months and six months after randomisation by an independent assessor who was blind to treatment group that the patient was allocated to.

3.2.5 Analysis Plan

Data from recruitment and six month follow-up assessments were analysed to determine which factors measured at recruitment were associated with severity of mood disorder at the time and six months later. At recruitment and six months follow-up scores on the BDI were dichotomised into mildly depressed (≤18) and severely depressed (≥19) in accordance with the manual (Beck & Steer, 1987). The BDI was used rather than the WDI as it has been more widely used in stroke research. It was not appropriate to use the continuous scores as the study only included patients who scored above the cut-off for depression, therefore the full range of scores on the scale would not have been used in the sample included in the treatment study. Also, for this reason non-parametric statistics were employed. Descriptive statistics were therefore calculated using the median and interquartile range. Chi-square tests were used to compare mildly and severely depressed patients on gender. Kruskall Wallis tests were used to compare patients according to side of lesion. Mann-Whitney U tests were used to compare the two groups of patients on age, BDI, WDI, GHQ-28, BI, RLOC, SST, and EADL scores.

At six months follow-up scores on the BDI were also dichotomised into depressed (BDI≤10) and not depressed (BDI≥11) in accordance with the manual (Beck & Steer, 1987). This was appropriate as at this time point some patients no longer

scored as depressed. This enabled the study of which factors assessed at baseline were related to patients being not depressed six months later. Chi-square tests and Mann Whitney U tests were repeated using these cut-off scores to compare depressed and non-depressed patients on factors measured at recruitment.

Logistic regression was used to assess which combination of factors at recruitment predicted severity of depression (mild or severe) at that time and also which factors predicted the presence of depression (depressed or not depressed) and severity of depression six months later. Logistic regression was appropriate as the outcome variable was a categorical dichotomy and the predictor variables were either continuous or dichotomous.

3.3 Results

The researchers sent questionnaires to 1144 patients. Questionnaires were not returned by 329 (28.76%) of the patients. One hundred and twenty three out of the 444 patients (27.70%) who returned the questionnaires and met the inclusion criteria were depressed on the BDI or WDI and consented to take part in the study. Sixty three were men (51.22%) and mean age was 66 years (SD=13.6). There were 112 patients assessed at both recruitment and six months follow-up and were included in this analysis.

At recruitment 77 (62.60%) of the 123 patients were mildly depressed (BDI≤18) and 46 (37.40%) were severely depressed (BDI≥19). Severity of depression did not significantly differ according to the time patients were recruited to the study (χ^2=4.52, p>.05) or treatment group allocation (χ^2=3.07, p>.05). Therefore data for the patients in different treatment groups and recruited at different time points were combined for the analyses. At six months follow-up, of the 112 patients who were reassessed, 84 (75.00%) were not depressed or were mildly depressed and 28 (25.00%) were severely depressed. Table 3.1 summarises the number of patients classified as not, mildly or severely depressed at recruitment and six months follow-up.

Table 3.1. Summary of number of patients classified as not, mildly or severely depressed on the Beck Depression Inventory at recruitment and six months follow-up

	Not depressed (BDI≤10)	**Mildly depressed** (BDI 10-18)	**Severely depressed** (BDI≥19)
Recruitment (n=123)	0	**77** (62.60%)	46 (37.40%)
6 months follow-up (n=112)	44 (39.29%)	40 (35.71%)	28 (25.00%)

BDI=Beck Depression Inventory

Descriptive statistics and comparison scores of mildly and severely depressed patients at recruitment and follow-up are shown in Table 3.2.

Table 3.2. Comparison of mildly and severely depressed patients on recruitment scores

	Recruitment			6 months follow-up		
	Mildly depressed n=77	Severely depressed n=46	Comparison p value	Not or mildly depressed n=84	Severely depressed n=28	Comparison p value
Gender						
Male	38	25	.59	44	15	.54
Female	39	21		40	13	
Age						
Mean	66.1	65.8	.87	67.1	61.7	.22
SD	13.1	14.6		12.2	17.4	
Side of weakness[1]						
Left	24	9	.16	14	8	.13
Right	14	11		26	4	
Bilateral	0	1		1	0	
BDI						
Median	n/a			14.5	22.50	<.001***
IQR				11.0-18.8	18.0-31.8	
WDI						
Median	21.0	25.0	<.001***	21.0	27.0	<.001***
IQR	18.0-23.5	21.0-28.0		19.0-23.0	24.0-30.0	
GHQ-28						
Median	27.0	44.0	<.001***	28.0	48.0	<.001***
IQR	21.5-36.0	32.0-54.5		22.0-37.0	35.0-55.0	
RLOC						
Median	25.0	23.0	.12	25.0	23.0	.02*
IQR	22.0-28.0	21.0-27.0		22.0-28.0	20.3-25.8	
Barthel						
Median	16.0	15.0	.17	16.0	15.0	.27
IQR	13.0-18.0	11.8-18.0		13.0-18.0	12.3-17.8	

	Recruitment			6 months follow-up		
	Mildly depressed n=77	Severely depressed n=46	Comparison p value	Not or mildly depressed n=84	Severely depressed n=28	Comparison p value
EADL total						
Median	28.0	21.0	.01**	27.0	21.5	.33
IQR	17.0-39.0	14.0-30.5		17.0-35.0	15.5-33.0	
EADL mobility						
Median	7.0	4.0	.01**	6.0	4.5	0.19
IQR	3.0-11.0	1.0-6.0		3.0-11.0	2.0-6.0	
EADL kitchen						
Median	10.0	8.0	.13	10.0	9.0	0.49
IQR	5.0-14.0	3.0-12.0		5.0-13.0	4.3-12.0	
EADL Domestic						
Median	4.0	2.0	<.01**	3.0	2.0	0.19
IQR	1.0-7.0	0-4.0		1.0-7.0	0-6.75	
EADL leisure						
Median	7.0	6.0	.54	7.0	8.0	.73
IQR	5.0-9.0	6.0-9.0		6.0-9.0	6.0-9.0	
SST						
Median	18.0	17.0	<.01**	19.0	17.5	.001***
IQR	18.0-19.0	16.0-19.0		18.0-19.0	16.0-18.0	

***p≤.001 **p≤.01 *p≤.05 [1] Data on side of weakness was not available for all patients.

Gender analysed using χ^2, side of weakness using Kruskall-Wallis, remaining analysed using Mann-Whitney U tests.WDI=Wakefield Depression Inventory, GHQ=General Health Questionnaire; BDI=Beck Depression Inventory; RLOC=Recovery Locus of Control Scale; EADL=Extended Activities of Daily Living Scale; SST=Sheffield Screening Test for Acquired Language Disorders, lower score indicates language impairment.

Patients who were severely depressed at recruitment scored significantly lower on the SST, EADL total, EADL mobility and domestic subscale scores ($p \leq .01$), and significantly higher on the WDI and GHQ at recruitment ($p \leq .001$) than mildly depressed patients. This means that severely depressed patients had more communication problems, lower independence in extended ADL and lower mood than mildly depressed patients.

Patients who were severely depressed at six months follow-up scored significantly higher on the BDI, WDI and GHQ ($p < .001$) and significantly lower on the SST ($p \leq .001$) and RLOC ($p < .05$) at recruitment than mildly depressed patients. Therefore, those who were severely depressed at follow up were more depressed, had more communication problems and an external locus of control at the time of recruitment compared with mildly depressed patients.

3.3.1 Predictors of depression severity at recruitment and six months follow up

In order to determine which combination of recruitment variables were significant predictors of depression severity at recruitment and at six months follow up, forward logistic regression was performed with severity of depression on the BDI (mildly or severely depressed) as the dichotomous outcome variable, and those variables which were significantly associated with severity as the predictor variables. The results of the logistic regression for recruitment and six months follow-up are summarised in Table 3.3.

Table 3.3. Summary of logistic regression for depression severity on the Beck Depression Inventory at recruitment and six months follow-up based on recruitment scores

Predictor	B	SE	df	Sig	Exp (B)	95% CI for Exp (B)	
Recruitment							
EADL mobility	-0.27	0.05	1	.59	0.97	0.88	1.07
EADL domestic	-0.12	0.06	1	.06	0.89	.079	1.00
SST	0.32	0.12	1	.01**	0.72	0.57	0.92
6 months follow-up							
BDI	.163	.039	1	<.001***	1.18	1.09	1.27
RLOC	-.07	.065	1	.251	.92	.818	1.05
SST	-.29	,17	1	.03*	.74	.57	0.98

EADL=Extended Activities of Daily Living Scale; RLOC=Recovery Locus of Control Scale; SST=Sheffield Screening Test for Acquired Language Disorders; BDI=Beck Depression Inventory
* $p \leq .05$ ** $p \leq .01$ *** $p \leq .001$

At recruitment, scores on the SST and the domestic and mobility subscales of the EADL at recruitment were entered into the regression simultaneously as predictor variables, as these were shown to be significantly different between depression severity at recruitment. Although scores on the WDI and GHQ were significantly different for the two groups of patients, they were not entered into the regression as they measure the same factors as the BDI (depressed mood), therefore their inclusion as predictor variables would be of little theoretical value. Scores on the SST were significant predictors of severity of depression on the BDI at recruitment (Wald $\chi^2(1)=6.99$, $p<.01$), with an odds ratio of 0.72. This means that for a one unit increase

in the SST (indicating less communication impairment) there was a 0.72 decrease in the odds of the patient being severely depressed. The EADL mobility and domestic subscales were not significant predictors in the regression model. The Nagelkerke R square for the model was 0.19. Field (2000) recommends that R^2 is calculated by dividing the final model χ^2 by the initial –2 log likelihood. Using this equation (17.621/158.775) the model accounted for 11% of the variance in depression severity at recruitment. The value for R can range between 0 and 1, with a higher score indicating that the predictor variables are better at predicting the outcome variable. Sensitivity (the proportion of people with severe depression who were classified as having severe depression by the model) of the model in correctly predicting depression classification was 0.44 and specificity (the proportion of people who were not severely depressed who were classified as not severely depressed) was 0.89. Using the model 72.5% of patients were correctly classified into the appropriate group (mildly depressed or severely depressed).

At six months follow-up SST and RLOC scores at recruitment were entered as predictor variables in the regression, as these were significantly different between patients mildly and severely depressed at six months follow-up. BDI scores at recruitment were also entered into the regression to control for the fact that SST scores were significantly different between mildly and severely depressed patients at baseline. If there is collinearity between BDI and SST scores at recruitment then one or both may not be a significant predictor in the regression. This will show whether the relationship between SST and depression severity at follow up is due to the relationship between SST and BDI at recruitment. BDI scores at recruitment were a significant predictor of depression severity at follow up (Wald χ^2 (1) =17.35,

$p<.001$). Scores on the SST at recruitment were also significant predictors of depression severity at follow up (Wald χ^2 (1) =4.82, $p<.05$), with an odds ratio of 0.74. This means that for a one unit increase SST scores (indicating less communication impairment there was a 0.74 decrease in the odds of the patient being classified as severely depressed. RLOC scores were not a significant predictor of depression severity in the regression. The Nagelkerke R square was 0.35. Using the equation of Field (2000) the model R^2 was (35.798/125.963) 28%. The model had sensitivity of 0.50 and specificity of 0.93 at predicting depression classification. Using the model 82% of patients were classified correctly into the appropriate depression severity.

3.3.2 Predictors of depression at six months follow-up

Patients were also classified into depressed (BDI>10) and not depressed (BDI≤10) on the BDI at six months follow-up to determine whether factors measured at recruitment could predict whether patients remained depressed six months later. Forty four (39%) of the 112 patients were not depressed on the BDI and 68 (61%) remained depressed at follow-up. Descriptive statistics and comparisons of the scores for those depressed and not depressed at six month follow-up are shown in Table 3.4.

Table 3.4. Comparison of depressed and non depressed patients at six months follow-up on recruitment scores

	Not depressed n=44	Depressed n=68	Comparison p value
Gender			
Male	22	37	.65
Female	22	31	
Age			
Mean	64.6	66.5	.23
SD	12.0	15.0	
Side of weakness			
Left	13	17	.51
Right	7	15	
Bilateral	0	1	
WDI			
Median	21.5	22.0	.06
IQR	18.3-24.8	20.0-26.8	
GHQ-28			
Median	26.0	37.5	<.001***
IQR	22.0-31.0	28.3-50.8	
BDI			
Median	13.00	18.0	.001***
IQR	11.0-18.8	15.0-22.8	
RLOC			
Median	26.0	23.0	<.01**
IQR	23.0-29.0	21.0-26.8	
Barthel			
Median	16.0	16.0	.69
IQR	13.0-18.0	13.0-18.0	

	Not depressed n=44	Depressed n=68	Comparison p value
EADL total			
Median	27.0	24.0	.42
IQR	17.0-36.5	16.0-35.0	
EADL mobility			
Median	6.5	5.0	.48
IQR	3.0-11.0	2.0-10.0	
EADL kitchen			
Median	10.0	9.0	.78
IQR	5.0-13.0	5.0-14.0	
EADL domestic			
Median	4.0	3.0	.28
IQR	1.25-7.0	0-6.0	
EADL leisure			
Median	7.5	7.0	.14
IQR	6.0-9.0	4.0-9.0	
SST			
Median	*19.0*	*18.0*	*<.01***
IQR	*18.0-19.0*	*16.0-19.0*	

***p≤.001 **p≤.01 WDI=Wakefield Depression Inventory, higher score indicates lower mood; GHQ=General Health Questionnaire, higher score indicates psychiatric morbidity; BDI=Beck Depression Inventory; RLOC=Recovery Locus of Control Scale, higher score implies more internal beliefs; EADL=Extended Activities of Daily Living Scale, higher score indicates greater independence; SST=Sheffield Screening Test for Acquired Language Disorders, lower score indicates language impairment.

Patients depressed at follow-up scored significantly higher than non depressed patients on the BDI (p≤.001) and GHQ (p<.001) at recruitment. Therefore, patients who remained depressed at follow up scored significantly lower than non depressed patients on the RLOC (p<.01), indicating a more external locus of control. Patients depressed at follow up also scored significantly lower on the SST (p<.01) at

recruitment than patients not depressed at follow up, indicating a greater degree of impairment in communication.

Forward logistic regression was performed with classification of depressed and not depressed at six months on the BDI as the outcome variable. Scores on the RLOC and SST at recruitment were entered as predictor variables as scores on these scales differed significantly between depressed and not depressed patients at recruitment. BDI scores at recruitment were also entered into the regression in the same manner as the analysis of baseline predictors of depression severity at follow up. Table 3.5 summarises the results of the logistic regression.

Table 3.5. Summary of logistic regression for depression at six months follow-up based on recruitment scores

Predictor	**B**	**SE**	**df**	**Sig**	**Exp (B)**	**95% CI for Exp (B)**	
BDI	.08	.034	1	.015*	1.09	1.01	1.16
RLOC	-.11	.05	1	.041*	.90	.81	0.98
SST	-.31	.16	1	.045*	.74	.54	1.00

BDI=Beck Depression Inventory; RLOC=Recovery Locus of Control Scale; SST=Sheffield Screening Test for Acquired Language Disorders.

* $p \leq .05$

BDI scores at recruitment were a significant predictor of depression at follow up (Wald χ^2 (1) =5.94, $p<.05$). Initial scores on both the SST (Wald χ^2 (1) =5.83, $p<.05$) and the RLOC (Wald χ^2 (1) =4.93, $p<.05$) were significant predictors of depression six months later. The odds ratio for the SST was 0.69 and for the RLOC was 0.89,

therefore patients with less communication impairment and a more internal locus of control were more likely to be not depressed at follow up. The Nagelkerke R square for the model was 0.18. The model R^2 was (22.968/150.082) 15% using the formula recommended by Field (2000). Sensitivity of the model was 0.75 and specificity 0.60 at categorizing patients as depressed or not depressed. The model correctly classified 70.5% of patients.

3.4 Discussion

About two-thirds of patients remained depressed at the follow up assessments. These patients were between seven and 13 months post-stroke. This is in accordance with the literature review which showed that depression was common in the first year after stroke. Patients who remained depressed at follow up were more depressed on the BDI when they were recruited. BDI scores at recruitment were the strongest predictors of depression and depression severity at six months follow up. This suggests that milder depressed mood is more likely to resolve over time while more severe depressed mood is persistent. Paradiso & Robinson (1999) proposed that there was a distinction between major and minor depression after stroke which have different time courses and risk factor. Robinson (1998) proposed that the course of major depression is less than one year while minor depression is more persistent. However, the findings of the present study do not support this view as patients with milder depression were more likely to have recovered at follow-up. There is little evidence to support the notion that major and minor depression after stroke are distinct disorders.

Patients with a lower level of perceived control over recovery and a greater degree of communication impairment when they were recruited were more likely to remain depressed six months later. The relationship between external locus of control and depression was in accordance with Morrison et al (2000), although in their study RLOC score was not predictive of depression outcome. However, Morrison et al (2000) assessed a whole stroke cohort, not only depressed patients. It could be argued that recovery locus of control and communication impairment at baseline were significant predictors of depression at follow up because both factors were also

associated with depression severity when patients were recruited (although RLOC scores were not significant). To account for this, BDI scores at recruitment were also entered into the regression analysis. RLOC and SST scores remained significant predictors of depression at follow up when baseline BDI scores were included in the regression. This implies that RLOC and SST were independent predictors of depression. This is because if the relationship were due to the fact that they were related to the BDI at recruitment then this collinearity would have led to the RLOC and SST not being significant in the regression model.

It is possible that locus of control may be also be associated with the coping behaviours that a patient employs. For example, patients who believe they have control over their recovery are likely to use more active coping strategies to address problems they encounter as they believe they can affect the situation they are in. Patients with an external locus of control will be more passive as they believe that others are responsible for their recovery. Johnston, Morrison, MacWalter & Partridge (1999) found no significant relationship between RLOC and coping in the first six months after stroke, but their only index of coping was engagement in physical exercise. A broader range of coping strategies including avoidant coping, which has been found to be associated with depression after stroke (Finset & Andersson, 2000; King et al, 2002), should be assessed simultaneously with RLOC and mood after stroke to explore the relationship between these factors.

Patients with severe communication impairment were excluded from the treatment study as they would have had difficulty participating in CBT. Consequently, the results of the study can only be applied to patients with mild or no communication

impairment. The finding that that SST scores were still an important predictor of depression severity and prognosis suggested that even though patients in this study were able to complete self-report measures and participate in the treatment trial, a small deviation from normal language ability affected patients' mood. This implies that even mild communication problems can affect mood, and this is consistent with the high levels of depression reported in aphasic patients (Kauhanen et al., 2000). Patients who have some degree of communication impairment could have difficulty interacting with others and being involved in activities requiring a high level of communication. This in turn may result in lower levels of positive reinforcement from others, which in turn may be associated with depression, in accordance with the behavioural model of depression. The findings have provided further evidence that communication impairment is related to depression after stroke. However, it is important that future studies should try and include patients with more severe communication impairment to explore this relationship further.

Hosking et al (1996) noted that depression may be a reaction to the realisation that some activities are more difficult to perform since the stroke. Independence in basic ADL was unrelated to depression at baseline and follow up. This is in contrast to about two thirds of studies in the literature that have reported severity of disability to be related to mood. However, the median scores on the Barthel Index were high, indicating higher levels of independence, as patients were not in hospital and were up to one year post-stroke at follow up. In addition to assessing basic ADL a measure of extended ADL was also included which was appropriate as most patients were living at home. Few studies in the literature have considered assessing activity level beyond self-care abilities. Performance of extended ADL was related to depression severity

at recruitment but this was not significant in the regression analysis. Ability to perform extended ADL, did not significantly differ between patients depressed and not depressed at follow up. This may be unexpected as the behavioural model would predict that lower activity levels will be related to depression as activities are expected to provide positive reinforcement and enhance feelings of self-esteem and mastery. The activity level of the sample was biased towards more able patients as those who scored less than 10 on the Barthel Index were excluded from the study. Extended ADL need to be assessed in a sample more representative of the range of disabilities of stroke patients in order to examine whether extended ADL are related to mood. It is also possible that the important factor may not be the level of disability *per se* but rather the extent to which pre-stroke activity levels have been disrupted. For example, Lewinsohn et al (1985) asserted that an individual would be depressed to the extent that 'scripted' (everyday behaviours) were disrupted. It would therefore be useful to obtain pre-stroke BI and EADL scores a indicators of pre-stroke activity levels in order to further explore the relationship between ADL impairment and depression.

Side of stroke was unrelated to depression. This supports recent reviews of the relationship between lesion location and depression (Carson et al, 2000; Singh et al, 1998), although data was not collected for all patients. Lesion location could not be explored further as no detailed measure of lesion location or characteristics was available. It has also been suggested that lesion location is an important predictor only in the acute stage post-stroke (Herrmann & Wallesch, 1993). Age and gender were unrelated to depression, and findings in the literature are inconclusive regarding

demographic factors, although studies that have found these to be related to distress have reported that they do not explain much of the variance in depression scores.

A possible criticism of the study is the use of a questionnaire measure instead of a structured diagnostic interview to classify depression. However, questionnaire scores have been found to be related to diagnostic interview (Aben, Verhey et al, 2002) and such measures are more easily replicable than other criteria (Collin et al, 1987). It is however important to note that the classification of patients as depressed was not equivalent to a clinical diagnosis of depression. Also, as the original study was designed to identify depressed stroke patients for a treatment trial it was most practical to assess a large number of patients by sending questionnaires by post to patients on a stroke register.

This study was limited as the patient sample was highly selected. All patients were included in a treatment trial, and therefore were depressed at recruitment. Appropriate patients were identified through sending out postal questionnaires of depression scales and almost one third of patients did not return them. As patients were required both to return the completed questionnaires and to consent to participate in the trial, it is possible that those patients who were willing to take part were more motivated to improve their outcome than those who declined and so had better mood. Also, patients with severe cognitive impairments may not have been able to complete and return the questionnaires independently. Moreover, patients with severe communication problems or who scored less than 10 on the Barthel Index were excluded, therefore the full range of communication abilities and levels of independence were not represented in the sample. Further prospective studies are

required to determine the factors that predict whether patients who are not depressed early after stroke become depressed later on in a more representative sample.

In conclusion, having mild communication problems was predictive of severity of mood on the BDI at recruitment and six months later. Furthermore, mild communication problems and an external locus of control in patients identified as depressed in the first six months after stroke were the strongest predictors of whether these patients would be depressed six months later. This is useful clinical information as it may aid the identification of patients at risk of remaining depressed in the first year after stroke and supports the importance of psychological factors in mood after stroke. However, the R square and the sensitivity for the models were low. This implies that other factors are important and should be explored in order to develop appropriate treatments. As demographic factors and ADL impairment at recruitment were not predictive of depression at follow-up, this suggests that future studies should investigate the contribution of other psychosocial factors. The risk factors for post-stroke depression are likely to be multifactorial (Whyte & Mulsant, 2002). Existing literature suggests that coping strategies (Finset & Andersson, 2000; King et al, 2002), social support (Knapp & Hewison, 1998; Morris et al, 1991) and cognitions (Nicholl et al, 2002) may also be relevant. These factors require further systematic investigation using a longitudinal design in a more representative sample of patients in order to aid our understanding of the risk factors for low mood in stroke patients. Also, the literature review for this thesis suggested that it is more relevant to look at overall emotional distress rather then focusing on anxiety or depressive disorders. This will inform the identification of patients vulnerable to distress after stroke and therefore guide approaches to prevent or alleviate distress.

4 CHAPTER 4 - FACTORS RELATING TO EMOTIONAL DISTRESS AFTER STROKE

4.1 Introduction to the study

The main study in this thesis was concerned with evaluating the theoretical framework proposed for the study of emotional distress after stroke. This framework was proposed following a review of the relevant literature and identified those factors which should be assessed to further understand distress after stroke. The first study in this thesis developed and validated a cognitions scale to explore the cognitive model of depression in stroke. The second study was secondary analysis of existing data to guide the main study conducted in a more representative sample. Communication impairment and recovery locus of control were found to be predictive of depression. Extended ADL were related to depression but were not significant in the regression model. However, the sample was not representative as it was taken from a treatment study and a depression measure (BDI) was used. This thesis has argued that it is more informative to study distress rather than diagnostic categories of anxiety and depression as distress and this was the focus of the main study. The main study assessed the constructs in the proposed theoretical framework to identify factors that were significantly related to emotional distress after stroke. Previous studies were limited as they were mostly cross sectional, were not always based on a theoretical rationale and generally only assessed one or two factors in isolation and psychological constructs have been largely overlooked. The findings of the present study will provide important information for making recommendations for therapeutic interventions to be evaluated to treat distress after stroke.

The research questions addressed by the present study were:

1. To identify which factors from the proposed theoretical framework assessed at baseline (one month after stroke) were significant predictors of distress at baseline.
2. To identify which factors from the theoretical framework assessed at follow up (six months after stroke) were significant predictors of distress at follow up.
3. To identify which factors assessed at baseline were significant predictors of distress at follow up.

4.2 Method

4.2.1 Methodological considerations

Methodological issues arise when conducting research with patients who have had a stroke and these were considered in the design of this study. Stroke patients are most frequently elderly and may experience a range of physical and cognitive difficulties which can impose limitations on study methodology. Patients may have limited concentration and be easily fatigued (Stroke Association, 2001). Assessments were therefore required which were brief and easy to administer, and the length of the assessment battery needed to take these factors into account. There are practical complications when assessing patients in hospital or at home and it is therefore advantageous if assessments can be conducted at a patient's bedside and do not require complex equipment.

The present study was concerned with the assessment of the severity of distress rather than with assessment for a clinical diagnosis of depression. Therefore, the main method for obtaining information about patient's mood was using standardised self-report scales, complemented by an observer-rated measure. The advantages of self-report measures are that they are brief and convenient, and if widely used, findings can be compared across studies. The use of a continuous measurement scale rather than a dichotomy ('depressed' versus 'not depressed') provided more detail about changes in mood. Also, it is likely to be more clinically meaningful to use assessment scales, as stroke services may be able to screen patients routinely with such measures, particularly when it is not feasible to offer a psychiatric interview to everyone (Herrmann et al, 1998). Self-report questionnaires were also selected to assess psychosocial factors such as coping strategies, locus of control and social

support. An alternative method would have been to use a semi-structured interview; however the use of questionnaire allows responses to be quantified in order to evaluate the proposed theoretical framework.

4.2.2 Design

The study was a prospective longitudinal design. This design was chosen to examine the factors related to distress in the first six months after stroke, to determine whether factors measured early after stroke were predictive of distress later on and whether factors related to distress changed over time. For this reason it was necessary to reassess the same patients at each time point. Assessments were first carried out when patients were between two weeks and one month after stroke and were repeated at six months after stroke. A two week time delay was deemed suitable as patients may experience transient adjustment reactions in the early days, rather than a more stable mood state. Patients may be medically unstable soon after admission to hospital and so it was not considered appropriate to recruit patients at this time. Also, patients are unable to give informed consent if they are confused in the early days after stroke. The follow-up assessment was conducted at six months after stroke, by which time most spontaneous recovery has occurred (Ebrahim & Harwood, 1999). Grieve, Dundas, Beech & Wolfe (2001) found that that average length of stay in an acute hospital was 35 days, therefore by six months most patients have been discharged from hospital and are adjusting to life post-stroke.

4.2.3 Participants

Patients admitted to stroke wards at Queens Medical Centre, Nottingham (ward F20), Nottingham City Hospital (Beeston Ward), Mansfield Community Hospital (Bayliss Ward) and the Derbyshire Royal Infirmary (Stroke Unit) between August 2002 and February 2004 were identified and invited to take part. These were the four local

hospitals with stroke units or wards where stroke patients were admitted for rehabilitation. Appropriate patients were identified through the researcher attending case conferences, consulting patient notes and on the advice of ward staff. Recruiting patients from hospital was considered appropriate as the majority of stroke patients are admitted to hospital and this allowed patients to be identified and approached early after stroke at a uniform point in time.

Inclusion and exclusion criteria

The criteria for inclusion in the study were chosen to allow a broad and inclusive sample most representative of the stroke population.

Patients were eligible for inclusion in the study if:

- They had been diagnosed with a stroke according to the World Health Organisation definition. This was required to ensure patients had been given a definite diagnosis of stroke, as patients with a suspected diagnosis may have subsequently been given an alternative neurological diagnosis.
- They were between two weeks and one month post-stroke. This criteria was needed to ensure patients were assessed at a uniform time. Reasons for this time point are explained in the section outlining the study design.
- They were well enough to be approached for consent/assent and complete the assessment. This was defined by the patient being conscious, alert, able to answer the questions and co-operate with assessments.

Patients were excluded from the study if:

- They were blind or deaf. This is because the assessments could not be administered to these patients in a standardised way.

- They had dementia documented in their medical notes prior to their stroke. This is because these patients may not have sufficient insight or may not provide reliable responses to the assessments. Also, any mood problems may have been related to the dementia rather than the stroke.
- They were unable to understand and speak English prior to their stroke as the assessments for the study were in English.

4.2.4 Description of assessments

The assessments used in this study are described and reasons for their selection justified. In addition to taking into account the length of assessments, demands on cognitive resources and practical issues, the attributes of the measures were considered. Wade (1992) noted that measures should be simple to improve compliance and reliability, and communicable to others. Assessments which have been used previously with stroke patients are preferred as this allows comparison with other studies. Guidelines upon which to evaluate measures for use in rehabilitation and stroke were taken from Wade (1992). These are briefly summarised and informed the choice of assessments in the present study.

1. Standardisation – whether there is method of consistent administration with clear instructions for its use.
2. Validity – whether the scale measures what it purports to measure. There are three main types:
    a) construct validity – whether it is related to other variables that it theoretically should concur with, and so measures the theoretical construct intended.
    b) criterion validity – whether the measure is tested against a 'gold standard'.

c) content validity – whether items relate to the construct being assessed and cover all facets of the construct.

3. Reliability – how reproducible the results of a scale is under different conditions (Streiner & Norman, 1995). This includes:

   a) test-retest reliability – whether responses are the same when retested over an interval where no change is expected.

   b) inter-rater reliability – whether different observers record the same score for the same patient.

   c) intra-rater reliability – whether the same assessor gives the same score for the same patients on separate occasions.

Table 4.1 summarises the assessment methods.

Table 4.1: Summary of assessment methods

Information	Source of information	Time point
Demographic details		
• Age	• Date of birth from medical notes	Baseline
• Employment status (previous occupation if not employed)	• Medical notes and confirmed with patient (carer if required)	Baseline & six months
• Marital status and living arrangements	• Medical notes and confirmed with patient	Baseline
Stroke details		
• Date of stroke	• Medical notes	Baseline
• Stroke classification	• Bamford classification from medical notes	Baseline
• Lesion location	• Medical notes	Baseline
Medical comorbidities		
• Previous stroke	• Medical notes	Baseline
• Previous depression	• Medical notes	Baseline
Pre-stroke functioning		
• Pre-stroke self-care	• Barthel Index for pre-stroke – medical notes or completed with patient (and/or carer help)	Baseline
• Pre-stroke extended activities of daily living	• Extended Activities of Daily Living Scale – completed with patient (and/or carer help)	Baseline
Language	• Sheffield Screening Test for Acquired Language Disorders – completed with patient	Baseline & six months
Activities of daily living (ADL)		
• Basic ADL	• Barthel Index – completed with patient (and/or carer help)	Baseline & six months
• Extended Activities of Daily Living	• Extended Activities of Daily Living Scale – completed with patient (and/or carer help)	Six months
Mood		
• Self-reported distress	• Hospital Anxiety and Depression Scale – completed with patient	
• Self-reported depression	• Visual Analogue Mood Scales – completed with patient	Baseline & six months
• Observer-rated depression	• Beck Depression Inventory-II – completed with patient	
	• Stroke Aphasic Depression Questionnaire – completed by ward staff or carer/relative	

Information	Source of information	Time point
Self-esteem	• Visual Analogue Self-Esteem Scale – completed with patient	Baseline & six months
Cognitions	• Stroke Cognitions Questionnaire Revised – completed with patient	Baseline & six months
Recovery Locus of Control	• Recovery Locus of Control Scale – completed with patient	Baseline & six months
Coping	• Brief COPE – completed with patient	Baseline & six months
Social support	• Significant others scale – completed with patient	Baseline & six months

4.2.5 Disability and pre-stroke disability

4.2.5.1 Barthel Index

(Collin et al, 1988)

The Barthel Index (BI) is a ubiquitous measure of independence in activities of daily living (ADL) in physically disabling conditions (Tennant, Geddes, & Chamberlain, 1996) and is probably the most widely used assessment of personal ADL in stroke. This 10-item index encompasses activities which need to be achieved for self-care and mobility. It covers five areas: excretion (bowels, bladder and toileting), mobility (transfer, walking and stairs), cleanliness, (grooming and bathing), feeding and dressing. For each item the individual responds with what they do, not potential functioning. Responses record level of independence; a four-point scale for mobility and transfer, a three-point scale for excretion, stairs, feeding and dressing, and a two-point scale for cleanliness.

This study used the scoring system developed by Collin et al (1988), whereby items were scored 0/1, 0/1/2, 0/1/2/3 according to the response categories. Items were

summed to give a maximum score of 20, with a higher score indicating greater independence. This was used in favour of the original scoring method (Mahoney & Barthel, 1965) in which items were scored in five point increments, giving a possible total of 100, as this latter scoring method may give a misleading impression of accuracy (Collin et al, 1988).

Studies have reported concurrent and predictive validity, with scores correlating with other ADL indices, and low scores predicting poorer outcome and activity levels (Wade & Langton-Hewer, 1987). Wade & Langton-Hewer (1987) found the items loaded onto a single factor, confirming internal consistency. Acceptable inter-rater reliability has been found between non-clinically trained researchers and nurses (Richards et al, 2000) and between self-report, nurses and skilled observers (Collin et al, 1988). There is evidence for test-retest reliability one week apart (Green, Forster, & Young, 2001). The BI has been found to be responsive to interventions in stroke (van der Putten, Hobart, Freeman, & Thompson, 1999).

The BI is preferable to more complex scales such as the Functional Independence Measure, which takes 30 minutes to administer and can require consensus of a multidisciplinary team (Granger & Hamilton, 1987). The Rivermead ADL scale (Whiting & Lincoln, 1985) can be administered using formal testing, does not include continence and the hierarchy changes with time and location (Wade, 1992). The Nottingham 10 point ADL index (Ebrahim, Nouri, & Barer, 1985) and the Northwick Park Index (Sheikh et al, 1979) are not widely used in stroke research and would preclude comparison to other studies. Also, the Nottingham 10 point ADL items are scored as dependent or independent and so does not indicate the level of

help required. Wade (1992) advocated the use of the BI as it covers the ten areas most commonly included in ADL scales, and is superior to the Katz ADL index (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) which only contains six items. The BI is recommended by the Royal College of Physicians for use in the elderly (Parker, Du, & Bardsley, 1994), and by the British Society of Rehabilitation Medicine (BSRM, 2000). The Barthel Index is used routinely in stroke and is familiar to ward staff, allowing comparison to other studies. The BI can be rated by any healthcare professional or by self-report. It is simple and quick to complete and score (about five minutes).

The BI score was routinely recorded in the medical notes by the nurses each week and was recorded from the medical notes by the researcher when the patient was assessed in hospital. For some patients the pre-stroke BI was also recorded in the medical notes, otherwise the patient or carer were asked to complete it during the first assessment with the patient. The BI was also completed with the patient (or the carer if the patient had severe communication problems) at the follow-up appointment. Items and responses were read aloud if required.

4.2.5.2 Nottingham Extended Activities of Daily Living Scale (Lincoln & Gladman, 1992; Nouri & Lincoln, 1987)

The Nottingham Extended Activities of Daily Living Scale (EADL) is a ranked scale developed to assess stroke patients' level of independence at performing extended activities of daily living in the community. Extended activities of daily living refer to activities that extend beyond basic self-care and include items such as making a hot drink, cooking and housework. The 22-item measure consists of four subscales: mobility (six items, e.g. 'Do you climb stairs?'); kitchen (five items, e.g. 'Do you do

the washing up?'); domestic (five items, e.g. 'Do you do your own shopping?') and leisure (six items, e.g. 'Do you go out socially?'). The scale records what patients have actually done, not potential functioning.

Responses were scored on a four point scale such that a response of 'No' scored 0, 'With help' scored 1 (0 and 1=dependent) while 'On my own with difficulty' scored 2 and 'On my own' scored 3 (2 and 3=independent). The present study used Likert scoring as it is more sensitive and Wade (1992) recommended that scoring responses 0-3 may be more useful than Guttman scoring. Scores for each sub-scale were obtained by summing items in that scale, and all 22 items were summed to give an overall total score between 0 and 66.

The subscales of the EADL have been shown to be valid and unidimensional, providing evidence of construct validity, and each subsection forms a hierarchical scale (Lincoln & Gladman, 1992). Test-retest reliability measured over two weeks was found to be excellent or good for 20 of the 22 items (Nouri & Lincoln, 1987). Predictive validity has been demonstrated by lower EADL scores being more common in those who were institutionalised or died over six months and concurrent validity inferred by EADL scores discriminating between patients at home or in institutions (Gladman, Lincoln, & Adams, 1993). The EADL is favourable to alternatives such as the Rivermead ADL which requires formal testing as a brief measure was needed. An alternative measure is the Frenchay Activities Index which includes social independence, but it requires recall of the previous six months rather than current functioning.

The EADL was recommended by the British Society of Rehabilitation Medicine (2000) for use in stroke and is the most popular measure of EADL in stroke (Turner-Stokes & Turner-Stokes, 1997). The Nottingham EADL was suitable for the present study as it was developed and validated for stroke and its widespread use allowed comparison to other studies.

The pre-stroke EADL was completed with the patient in hospital. The EADL was completed at six months after stroke. Questions and responses were read aloud if required. For aphasic patients the EADL was completed with assistance from a carer/relative. The scale took between five and ten minutes to complete.

4.2.6 Aphasia

4.2.6.1 Sheffield Screening Test for Acquired Language Disorders

(Syder et al, 1993)

The Sheffield Screening Test for Acquired Language Disorders (SST) was developed to identify the presence of high-level language disorders in adults. The SST is a short and simple assessment that was used in this study to screen for language difficulties and determine whether patients should receive a full assessment. It is a bedside screening instrument suitable for use by a researcher who does not have training in linguistics. The SST has two sections: 1) receptive language skills and 2) expressive language skills. Section one requires the patient to make verbal and non-verbal responses to questions of increasing complexity, such as verbal comprehension of single words and a sequential command, recognition of differences in meaning between words and comprehension of a short narrative. The second section requires verbal responses of graded complexity such as word-finding, sequencing, defining words and verbal reasoning.

Performance was scored according to the manual (Syder et al, 1993). A correct answer scores one point, except for questions 1, 6 and 8 which require several correct responses. The maximum score for receptive skills is nine and for expressive skills 11, with a maximum total score of 20. The authors of the scale recommend age-related cut-offs of 17/20 for ages 59 and under, 16/20 for 60-69 years and 15/20 for 70 and over; scores lower than the cut-off indicate language difficulties (Syder et al, 1993).

Normative data and data from stroke patients are available in the manual. There is evidence that the SST can accurately identify the presence of language disorders and scores on the SST were correlated with the Shortened Token Test (Syder et al, 1993). Inter-rater reliability between physiotherapists, nurses and student was found to be good (Syder et al, 1993). Comparison of the SST with the Frenchay Aphasia Screening Test (FAST) in stroke and traumatic brain injury patients found significant correlations between receptive skills on the SST and comprehensions skills on the FAST, between expressive skills in the two tests, and between total scores (Al-Khawaja, Wade, & Collin, 1996). The SST had 89% sensitivity, 100% specificity and 90% accuracy in detecting aphasia confirmed by a speech therapist and these values were superior to the FAST. The SST may be considered advantageous as it does not require stimulus cards or equipment, and is unaffected by visual neglect. The SST has been used in stroke research and Blake et al (2002) recommended the SST as a brief screening measure for language difficulties in stroke.

The SST was administered to the patient following standardised instructions. Items were repeated once if required. The assessment took approximately five minutes to complete.

4.2.7 Emotional distress

4.2.7.1 Hospital Stroke Aphasic Depression Questionnaire (SADQ-H)

(Lincoln et al, 2000)

The SADQ-H was developed to assess mood in aphasic patients using ratings of observed behaviours indicative of low mood. This is valuable for aphasic patients who frequently can only be assessed using visual analogue scales. It was completed in the present study for both aphasic and non-aphasic patients to allow comparisons and so that analysis could be performed on the whole sample. This study used the 21-item hospital version (Lincoln et al, 2000) as this has been validated in hospitalised stroke patients and was more highly correlated with the Wakefield Depression Inventory (WDI) than the community version.

The SADQ-H contains 21 items, each describing behaviours observed in stroke patients that may be associated with low mood, for example "Did he/she initiate activities?", and it refers to the last seven days. Each item has four response options: 'every day this week', on '4-6 days this week', 'on 1-4 days this week' and 'not at all this week'. Each item was scored from 0-3. Items 1, 2, 3, 5, 6, 8, 9, 10, 11, 13, 14 and 19 score three for 'every day this week' and 0 for 'not at all this week' and scoring is reversed for the remaining items. Scores were summed to give a total of 0-63, with a higher score indicating lower mood.

The SADQ-H has high internal consistency (Cronbach's alpha 0.82) (Lincoln et al, 2000). Patient and nurse ratings of behaviours were significantly correlated, implying correspondence between the patients' and nurses' rating of mood. SADQ-H and WDI scores by the nurses were significantly correlated (Lincoln et al, 2000). The Hospital SADQ can therefore be considered to provide an accurate assessment of subjective mood. It was developed for stroke patients and was therefore suitable for this study. Turner-Stokes and Hassan (2002) recommended the SADQ in an integrated care pathway for depression in stroke to describe emotional behaviour in patients who cannot give verbal responses. An alternative observer rated scale developed for stroke is the Signs of Depression Scale (SODS) (Watkins et al, 2001). The SODS assesses the presence or absence of six observed symptoms but it is not widely used and the use of yes/no responses may be too restrictive. The SADQ-H is a useful tool for nursing staff to assess patient behaviour, and responses correspond well with patient experience (Lincoln et al, 2000).

The SADQ-H was completed by the patient's named nurse while the patient was in hospital and by a carer/relative/friend who had the most contact with the patient when they were discharged. If the carer/relative were not present when the patient was assessed at follow-up then the SADQ-H was left with a pre-paid envelope so it could be returned by post, and this was followed up with a telephone reminder if it was not returned within five days of the assessment.

4.2.7.2 Visual Analog Mood Scales (VAMS)

(Stern, 1997)

Self-report measures of mood may be unsuitable for aphasic patients due to their reliance on intact language skills. In addition to an observer rating of mood, a valid

assessment of internal mood state is important (Stern, Arruda, Hooper, Wolfner, & Morey, 1997). The VAMS is a non-verbal assessment of internal mood states designed for neurological patients, particularly those with significant language problems. The VAMS was administered in the present study to obtain a measure of internal mood from aphasic patients and was also administered to non-aphasic patients to allow comparisons and so analysis could be performed on the whole sample.

The VAMS has eight unipolar scales presented on separate pages (afraid, confused, sad, angry, energetic, tired, happy and tense), each consisting of a 100mm vertical line. At the top of the line is a 'neutral' line drawing of a face with the word "Neutral" above it. The 'mood' face is at the bottom of the vertical line with its corresponding verbal label below it. The verbal label may provide additional information to patients with single word recognition ability (Stern, 1997). For each item the patient is required to mark the vertical line to indicate the extent to which they are 'feeling' each mood state at the present time.

Each item was scored by measuring the distance in millimetres from the neutral end of the vertical line to the mid-point of the patient's mark. The score ranged from 0-100, with higher scores indicating greater endorsement of that mood state. Raw scores for the eight scales can be summed to give a composite score, with scoring reversed for the happy and energetic items (Nyenhuis, Stern, Yamamoto, Luchetta, & Arruda, 1997) and this was used in the present study. A raw cut-off score of 50 on the sad subscale in relation to a formal diagnosis of depression has been found to

have sensitivity of 0.78 and specificity 0.88, although this should not be interpreted as a clinical diagnosis of depression (Stern, 1997).

Normative data is available for general adult and geriatric standardisation samples (Nyenhuis et al, 1997; Stern, 1997). Convergent and discriminant validity have been found in stroke patients (Arruda et al, 1999) students (Stern et al, 1997), and adult and geriatric samples (Nyenhuis et al, 1997). Test-rest reliability correlations in stroke patients have been reported to be high (Stern, 1997), with a mean of 0.75 (Arruda, Stern, & Somerville, 1999), and high test-retest correlations were found in multiple sclerosis (MS) patients in the community (Groom, Lincoln, Francis, & Stephan, 2003). Correlations were significant between the repeated assessments when the first presentation excluded the verbal label, suggesting the scale is suitable for aphasic patients (Stern, 1997). The VAMS correlated significantly with the Visual Analogue Self-Esteem Scales in MS patients (Groom et al, 2003). In adults and geriatric patients a two-factor structure has been found – 'negative mood' and 'energy' (happy and energetic) (Nyenhuis et al, 1997). The VAMS distinguished between psychiatric patients with depression and anxiety, indicating discriminant validity (Stern, 1997). The VAMS has been shown to be sensitive to depression treatment in stroke patients (Arruda et al, 1997).

The VAMS may be useful in primary care and medical settings when a brief measure is required (Nyehnhuis et al, 1997), and it was suitable for this study as it enabled internal mood state to be assessed in aphasic patients. It was also appropriate as it has a consistent response format and places low demands on memory as it assesses current mood state. The VAMS has been validated in stroke patients (Arruda et al,

1999). Bennett et al (In press) found in a sample of stroke patients that the internal consistency of the scale was improved when the 'happy' and 'energetic' items were removed, therefore in the present study the VAMS total was calculated with these two items excluded.

The VAMS was administered by the researcher according to the manual. The researcher read aloud the directions and read through the practice item with the patient. The scale took between five and ten minutes to complete.

4.2.7.3 Visual Analogue Self-Esteem Scale

(Brumfitt & Sheeran, 1999b)

The Visual Analogue Self-Esteem Scale (VASES) was developed to assess self-esteem in aphasic patients, as existing self-report measures rely on intact language. The VASES is a 10-item scale; each item consists of a pair of pictures presented side by side horizontally on an A4 sheet with a verbal label above each picture. Each picture represents the opposing end of the construct: not being understood/understood, not confident/confident, cheerful/not cheerful, outgoing/not outgoing, mixed up/not mixed up, intelligent/not intelligent, angry/not angry, trapped/not trapped, not optimistic/optimistic and frustrated/not frustrated. Participants respond on a five-point Likert-type scale which is below the two pictures, choosing the sign below the picture which best describes them (++ very true of me; + true of me) or choosing the midpoint (in between).

Each item is scored from one to five (one corresponding to the most negative response and five to the most positive response). The score was also recorded for the example item (depressed/not depressed) as the total score including the depression

item has been found to have higher internal consistency than without it (Bennett et al, in press). Responses are summed to give a total score. Including the depression item the minimum score is 11 and maximum 55, with a higher score indicating higher self-esteem.

The items for the VASES were developed from the study of personal constructs of people with aphasia and from existing self-esteem measures, which suggests content validity (Brumfitt & Sheeran, 1999b). Internal consistency was found to be high in language impaired patients, both for those who did and did not receive the verbal labels, suggesting the scale is appropriate for use with more severely impaired aphasics (Brumfitt & Sheeran, 1999a). Test-retest reliability was found to be high in a student sample (Brumfitt & Sheeran, 1999a) and in patients with multiple sclerosis (MS) (Groom et al, 2003). There is evidence of good construct validity as the 10 items were found to load on one factor (Brumfitt & Sheeran, 1999a) and convergent and discriminant validity. The VASES have been shown to correlate with the Visual Analogue Mood Scales in student populations (Brumfitt & Sheeran, 1999a) and MS patients (Groom et al, 2003), and with the depression subscale of the HADS in stroke patients (Okirie, 2003). Bennett et al (in press) found that in a sample of stroke patients the internal consistency of the VASES increased when the depression item (the example item) was included and recommended the VASES as a screening measure of distress in stroke. Therefore the VASES total was also calculated including the depression item to provide a measure of emotional distress.

The scale is short and easy to administer, has a consistent response format, and places little demands on memory. There is no alternative non-verbal measure of self-

esteem. Therefore, the VASES was used in the present study as it was appropriate for administration to patients with communication problems.

The researcher completed the VASES with the patient. The researcher looked at the two pictures and corresponding labels with the patient. The symbols on the rating scale were explained to the patient. The patient was asked to consider which of the two pictures was most like them. Once the patient had chosen the appropriate picture they were asked which symbol on the rating scale corresponded to how they were feeling. The VASES took about five to ten minutes to complete.

4.2.7.4 Beck Depression Inventory – II (BDI-II)

(Beck et al, 1996)

The Beck Depression Inventory (BDI; Beck et al, 1987) is a well-established and widely used measure of depressive symptoms in psychiatric patients and normal populations (Beck, Steer, & Garbin, 1988). It has also been widely used in stroke (e.g. Anderson et al, 1995; Dam et al, 1989; House et al, 1991; Kotila et al, 1998, 1999; Pohjasvaara et al, 2001; Rochette & Desrosiers, 2002). The BDI was updated to the BDI-II to be consistent with DSM-IV (Beck et al, 1996). The BDI-II is a 21-item self-report instrument assessing mood over the past two weeks. Each item consists of four self-evaluative statements of increasing intensity (for example 'I do not feel sad' to 'I am so sad or unhappy that I can't stand it') and the patient is required to indicate which statements best describes how they have been feeling in the past two weeks. Symptoms include sadness, pessimism, loss of pleasure, self-dislike, suicidal thoughts, crying, irritability, changes in sleep pattern and appetite. Each item is scored on a four point scale ranging from 0-3, a score of 0 corresponding to the first statement and three to the last and most intense statement.

Scores for each item are summed to give a total score from 0-63, with a higher score indicating lower mood. Cut-off scores have been recommended: 0-13 minimal; 14-19 mild depression; 20-28 moderate depression; 29-63 severe depression (Beck et al, 1996). Items 2, 3, 5-9 and 14 can be summed to give a cognitive subscale score and the remaining items can be summed to provide a somatic-affective subscale (Steer, Ball, Ranieri, & Beck, 1999).

Beck et al (1996) reported very good test-retest reliability, high internal consistency, discriminative validity and moderate-high convergent validity. Content validity is inferred by the fact that the items were designed to concord with DSM-IV criteria. BDI-II scores correlated significantly with the Beck Hopelessness Scale and Hamilton Depression Rating Scale (Beck et al, 1996), supporting construct validity. The BDI-II has been shown to consist of an underlying second-order factor of self-reported depression which consists of two first-order factors of cognitive and noncognitive symptoms in student samples, depressed outpatients and depressed geriatric inpatients (Beck et al, 1996; Dozois, Dobson, & Ahnberg, 1998; Steer, Ball et al, 1999; Steer, Rissmiller, & Beck, 2000). Internal consistency is high for the cognitive-affective and somatic subscales (Whishman, Perez, & Ramel, 2000). Depression severity did not correlate with age or gender, supporting the use of the BDI-II in the present study where a majority of the patients are elderly (Beck et al, 1996).

Use of the BDI-II in stroke patients may be criticised due to the somatic items. In primary care medical patients convergent validity was found with the Short-Form General Health Survey, and internal consistency was high (Arnau, Meagher, Norris,

& Bramson, 2001). BDI-II also corresponded with a diagnosis of major depression. The two-factor model of cognitive and somatic-affective symptoms was also found in primary care medical patients and item-total correlations were not lower for somatic items (Arnau et al, 2001). Studies of the original BDI with neurological patients including stroke found the scale an acceptable screening instrument (Aben, Verhey et al, 2002; Aikens et al, 1999; Lykouras et al, 1998). The BDI-II has also been used in patients with traumatic brain injury (Glenn, O'Neil-Pirozzi, Goldstein, Burke, & Jacob, 2001) and it is sensitive and moderately specific for depression in a primary care medical setting (Arnau et al, 2001). The BDI-II has been shown to be sensitive to the effects of antidepressant treatment in patients undergoing brain injury rehabilitation (Turner-Stokes, Hassan, Pierce, & Clegg, 2002).

The BDI-II was selected for the present study as it is a well-established and widely recognised measure of mood, and there is evidence of reliability and validity in psychiatric and medical patients. Furthermore, Turner-Stokes and Hassan (2002) recommended the BDI-II as part of an integrated care pathway to assess mood in stroke patients. The researcher completed the BDI-II with the patient. Instructions and statements were read aloud to the patient who then indicated which statement was most appropriate. The assessment took up to 10-15 minutes to complete.

4.2.7.5 Hospital Anxiety and Depression Scale (HADS)

(Zigmond & Snaith, 1983)

The HADS is a self-assessment mood scale designed to exclude physical indicators of psychological distress and it was developed to identify possible caseness of anxiety and depression in non-psychiatric hospital settings. The scale contains 14 items consisting of anxiety and depression subscales (seven items each). Responses

are on a four point scale of graded severity that differs for each item. The odd-numbered items are anxiety, and the even numbers depression. Responses refer to mood in the last week.

Each item is scored 0-3 depending on whether the item is worded in a positive or negative direction. Items are summed to provide subscale scores, with scores ranging from 0-21 for each subscale. Higher scores indicate problems with mood or anxiety. This study used the cut-off of 6/7 which was recommended for stroke patients (O'Rourke et al, 1998). The HADS total score (anxiety and depression subscales combined) was also calculated to provide overall measure of emotional distress. The total score has been used as a global measure of psychological distress with cancer patients and cardiac patients (Roberts, Bonnici, Mackinnon, & Worcester, 2001; Smith et al, 2002; Spinhoven et al, 1997) and with stroke patients (Aben, Verhey et al, 2002; Johnston, Pollard, & Hennessery, 2000; Townend, 2004), with high levels of sensitivity and specificity for detecting cases. A review of 18 studies in various patient groups found a mean correlation of 0.63 between the anxiety and depression subscales (Herrmann, 1997) and a similar pattern was found by Bjelland, Dahl, Haug and Neckelmann (2002). Anxiety and depression subscales correlated significantly in stroke (Gillespie, 1997; Townend, 2004). It has been proposed that the HADS has a hierarchical structure: two secondary factors of anhedonia and autonomic anxiety, and these are subordinate to a third factor psychological distress (Dunbar, Ford, Hunt, & Der, 2000; Smith et al, 2002; Spinhoven et al, 1997). The high level of covariance between the anxiety and depression subscales supports the assumption that the subscales share a distress component (Townend, 2004).

A review of studies found high internal consistency for both the anxiety (0.68-0.93) and depression (0.67-0.90) subscales (Bjelland et al, 2002) and internal consistency was high in stroke patients (0.7-0.89) Johnston et al (2000). Use of the HADS in patients with stroke, breast cancer and myocardial infarction supported an underlying psychological rather than somatic structure (Johnston et al, 2000). It has also been found to be sensitive to therapy to treat depression in stroke (Dennis, O'Rourke, Slattery, Staniforth, & Warlow, 1997). Comparison of the HADS with the GHQ-30 found no significant difference between the GHQ-30 total score and the HADS total score in their ability to detect DSM-IV depression or anxiety at six months after stroke (O'Rourke et al, 1998). The HADS is shorter and quicker to complete than the GHQ-30 and was designed for use in a hospital setting. The HADS has been widely used in hospitalised and community stroke populations (Ellis-Hill & Horn, 2000; Gillespie, 1997; Knapp & Hewison, 1998; Morrison et al, 2000; O'Rourke et al, 1998; Sharpe et al, 1994), allowing comparisons to other studies. The scale provided an assessment of both anxiety and depression, and of overall distress.

Patients completed the HADS, with the researcher, according to the instructions on the question sheet. Statements and responses were read aloud if required. The scale took about five to ten minutes to complete.

There are many self-report scales of mood. When choosing appropriate scales for this study the main considerations were whether the measure had been validated and used in stroke and other non-psychiatric populations. The length of the assessment was also considered. Alternative mood assessments to those chosen for this study include the Wakefield Depression Inventory which has been used in stroke research (Collin

et al, 1987; Wade et al, 1987), but it is not as widely used as the BDI/BDI-II and the HADS in stroke and in patients with physical disabilities. The General Health Questionnaire has also been used in stroke (e.g. Collin et al, 1987; O'Rourke et al, 1998; Dennis et al, 2000) but was developed to assess 'caseness' rather than distress. The Geriatric Depression Scale (GDS) (Yesavage et al, 1983) is a 30-item measure designed for the elderly but due to its length is less popular. The shortened GDS (15 items) contains some items not appropriate for stroke patients as they may reflect the effects of stroke rather than mood ('Have you dropped any of your interests and activities?'), patients find it difficult to categorise responses as yes or no and it has not been validated in stroke.

4.2.8 Cognitions

4.2.8.1 Stroke Cognitions Questionnaire Revised

The Stroke Cognitions Questionnaire Revised (SCQR) was developed and validated in Chapter 2 of this thesis. In summary, the SCQR is a 21 item scale that measures the frequency of positive (nine items) and negative (12 items) cognitions. The scale was developed from the treatment notes of depressed stroke patients who received cognitive behaviour therapy and so the items are relevant to stroke. For details on the reliability and validity of the scale, please see Chapter 2 of the thesis.

4.2.9 Locus of control

4.2.9.1 Recovery Locus of Control Scale

(Partridge & Johnston, 1989)

The recovery locus of control scale (RLOC) was developed to measure the internality/externality of a person's perceptions of control over their recovery from physical disability. The RLOC contains nine statements about recovery; items 1, 3, 5,

7 and 9 reflect *internal* beliefs (e.g. "It's what I do to help myself that's really going to make all the difference") and the remaining items reflect *external* beliefs (e.g. "My own contribution to my recovery doesn't amount to much"). For each statement the patient indicates the extent to which they agree or disagree with it. Responses are on a five point Likert-scale: strongly agree, agree, uncertain, disagree and strongly disagree. Internal items are scored from five to one with 5='strongly agree' and 1='strongly disagree' and scoring is reversed for external items. The scores for the nine items are summed to give a total score ranging from 9-45, with a higher score indicating a more internal locus of control.

Items were derived from statements made by stroke and wrist fracture patients about recovery, suggesting content validity (health psycho portfolio). Validity was evaluated in stroke and wrist fracture patients (Partridge & Johnston, 1989). Item subscale correlations ranged from 0.49-0.75 for internal items and 0.49-0.80 for external items. Internal scores were negatively correlated with external scores. Internal consistency has been reported to range from 0.53 to 0.77 (Johnston et al, 1999). Higher internality scores were positively correlated with progress in recovery from disability, indicating predictive validity (Johnston et al, 1999; Partridge & Johnston, 1989). Other locus of control scales exist, such as the Health Locus of Control Scale and the Multidimensional Health Locus of Control scale but these assess health control and are more applicable to health prevention behaviours. The advantage of the RLOC is that it assesses health-related cognitions rather than theoretical or general control cognitions.

The RLOC was suitable for the present study as it is specifically concerned with recovery from physical disability. It is quick and simple to complete so is suitable for a clinical setting, and does not require retrospective reports. The scale was developed in stroke patients and has been used in subsequent stroke studies (Frank, Johnston, Morrison, Pollard, & MacWalter, 2000; Johnston et al, 1999; Morrison et al, 2000) thus allowing comparisons. It has also been used in disabling conditions such as multiple sclerosis and spinal cord injury (Macleod & Macleod, 1998). It has been found to be sensitive to interventions designed to manipulate locus of control in stroke (Johnston et al, 1992).

The patient completed the RLOC with the researcher. Each statement was read to the patient and they indicated their response. Responses were marked by either the researcher or the patient. The scale took between five and ten minutes to complete.

4.2.10 Coping

4.2.10.1 Brief COPE

(Carver, 1997)

The COPE is a 60 item multidimensional coping inventory developed using two theoretical models: Lazarus' model of stress and a model of behavioural self-regulation. This study used the Brief COPE which is a shortened version of the coping scale that was developed by Carver (1997) as the original scale had item redundancy and was lengthy to complete. The Brief COPE is a 28-item scale consisting of 14 subscales (self-distraction items, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion

and self-blame) each containing two items. The author retained those items from the original scale which had a high loading on the relevant factor and which were easy to communicate. The scale includes some responses that are thought to be functional and some which are dysfunctional, and it incorporates emotion-focused and problem-focused strategies. Scales 2, 5, 6 and 9-13 can be regarded as adaptive, and the remaining items maladaptive (Meyer, 2001).

The respondent was required to rate each statement on a four point scale to describe the extent to which they have been using each coping method in the past month: 1='I haven't been doing this at all', 2='I've been doing this a little bit', 3='I've been doing this a medium amount' and 4='I've been doing this a lot' and items are scores from 1-4. Summing of items to give an overall score was not endorsed by Carver (1997). In this study scales were grouped to give scores for adaptive and maladaptive coping as recommended by Meyer (2001).

The Brief COPE was validated in individuals who survived a major hurricane. For each of the 14 scales alpha values were 0.5-0.9, suggesting moderate to high internal consistency (Carver, 1997). Internal consistency has been reported to be >0.6 in psychiatric patients (Meyer, 2001) and in myocardial infarction patients (Bennett et al, 1999). Meyer (2001) found internal consistency to be high for the adaptive coping scale (0.81), and slightly lower for the maladaptive scale (0.57). The Brief COPE has also been validated in breast cancer patients with high internal consistency and test-retest correlation and it correlated with the Coping with Health Injuries Profile, providing evidence of construct convergent validity (Fillion, Kovacs, Gagnon, & Endler, 2002). Shen, McCreary & Myes (2004) found a two-factor structure similar

to the secondary factor analysis of Carver, Scheier and Weintraub (1989), with items grouped to reflect negative (maladaptive) coping and active coping.

An alternative coping assessment is the Ways of Coping Questionnaire. The WCQ was designed to assess a broad range of coping behaviours over a longer time period and thus was not considered appropriate for this study. Also, the WCQ may not be suitable for clinical populations as it is not be relevant for all situations and the response key can be ambiguous (Fillion et al, 2002). Internal consistency and test-retest reliability of the WCQ is not always satisfactory (Schwarzer & Schwarzer, 1996). A strength of the Brief COPE may also is that it contains separate scales for different components of active coping while the WCQ has a single scale for this (Carver et al, 1989). The Brief COPE assesses a broad range of strategies and is less burdensome to complete (Meyer, 2001).

The Brief COPE covers a range of strategies and includes scales of theoretical interest and reliability and validity have been demonstrated in physically ill populations. The COPE and Brief COPE have predicted clinically relevant outcomes in several populations (e.g. Carver, 1997; Fillion et al, 2002; Lowe, Norma & Bennett, 2000; Meyer et al, 2001; Shen et al, 2004). Furthermore, the COPE subscales were uncorrelated with social desirability (Carver et al, 1989). There is no gold standard for the assessment of coping. The Brief COPE was chosen for the present study as it is a reasonably brief scale covering a broad range of strategies, with evidence of reliability and validity in physically ill populations.

The patient completed the Brief COPE with the researcher. The instructions at the top of the sheet were read to the patient and each item was read out by the researcher. The questionnaire took about ten minutes to complete.

4.2.11 Social Support

4.2.11.1 Significant Others Scale (Power, Champion & Aris, 1988)

The Significant Others Scale (SOS) was developed to examine the quality of an individual's most significant relationships. The short form was used, as recommended by the authors (Power, 1988; Power, Champion, & Aris, 1988). The short form SOS includes four support functions; two emotional (item 1 and item 2) and two practical (items 3 and item 4). For each item the patient is required to rate on a seven point scale a) the level of support received and b) their ideal rating for this support. This study used the SOS version B in which the patient can select up to seven individuals to provide ratings about. For the purpose of this study the individual was required to name up to three individuals who were important in their life, this was to reduce the length of the assessment, and because some named individuals may not be applicable to elderly patients (e.g. mother and father).

For each item the patient is asked to rate on a seven point scale a) how well the person provided that particular type of help, and b) what their ideal rating is (1='never' to 7='always'). Raw scores can be obtained for each individual for each type of support. Mean scores are obtained by summing scores for each type of support and dividing this by the number of individuals (three in this study). A score of *actual* emotional support is obtained by summing the scores from items 1a and item 2a and the amount of actual practical support by summing 3a and item 4a. In a similar way an *ideal* score is obtained by summing the ideal ratings for emotional (1b

and 2b) and practical support (3b and 4b). A *discrepancy* score for both emotional support and practical support is calculated by subtracting the *ideal* score from the *actual* score. This is an index of satisfaction with that type of support.

The emotional and practical items on the scale have been found to be separate using factor analysis (Power et al, 1988). Test-retest correlations over a six month interval were high, (Power et al, 1988). Evidence for criterion validity was obtained by showing that depressed patients had greater ideal ratings and discrepancy scores and non depressed patients (Power et al, 1988, Power, 1988). There is also evidence of predictive validity, the level of support being a significant predictor of depression six months later (Power, 1988).

The SOS has been used in stroke (Blake & Lincoln, 2000). Knapp and Hewison (1998) assessed social support in stroke patients using the Interview Schedule for Social Interaction; this is a more complex measure that is lengthy to complete. The advantages of the SOS are that it has been carefully developed and provides measures of practical and emotional support, in addition to an index of satisfaction. It is quick to administer and easy for patients to understand.

The researcher completed the SOS with the patient following the instructions on the sheet. Questions and responses were read aloud if required. The scale took about five minutes to complete.

4.2.12 Ethical considerations

The Research Ethics Committees of Nottingham City Hospital, Queens Medical Centre Nottingham, Mansfield Community Hospital and the Derbyshire Royal Infirmary granted ethical approval for this study to take place. Patients were included in the study if they provided informed consent, or assent was provided by a carer/relative for those patients with severe communication problems. The researcher (ST) explained the study to the patients while they were on the hospital ward and gave them an Information for Patients sheet. In accordance with ethical guidelines patients were given at least 24 hours to decide whether they wished to take part. Patients who agreed signed a consent form and were provided a copy of the information sheet and signed consent form to keep. For patients with severe communication problems, the study was also explained to a relative/carer of the patient and assent was sought. Ward staff were consulted to ascertain whether a carer or relative should be approached for assent. The researcher explained to patients that participation in the project was voluntary, that they could withdraw from the study at any time without giving a reason, and that the standard of care they received would be unaffected if they did not take part. This was detailed in the information sheet, in addition to assurance that data collected was anonymous and confidential.

4.2.13 Procedure

All patients who met the inclusion criteria were invited to take part in the study. Patients who provided informed consent, or for whom assent was obtained, completed a battery of assessments with the researcher on the hospital ward. All patients were first screened on the Sheffield Screening Test for Acquired Language Disorders (SST) (Syder et al, 1993). The SST was used as measure of language difficulties to determine which patients would be appropriate to complete self-report measures that require intact language abilities, and which patients should only be

assessed on scales appropriate for individuals with communication problems. Patients who scored below the cut-off for their age on this assessment were classified as 'aphasic'. The recommended cut-offs are: 17/20 for ages 59 and under, 16/20 for ages 60-69 years and 15/20 for ages 70 and over. The classification of patients into 'aphasic' and non-aphasic' was not intended as a clinical diagnosis in the present study, but it provided an objective method of classifying patients with language problems.

Patients completed a series of assessments with the researcher. All patients were assessed on the Visual Analogue Mood Scales (Stern, 1997) as a measure of mood and the Visual Analogue Self-Esteem Scale (Brumfitt & Sheeran, 1999b) as an assessment of distress. The Barthel Index (Collin et al, 1988) of basic self-care abilities was recorded from the medical notes. The Barthel Index was completed by staff for each patient on a weekly basis in each of the hospitals. The Hospital Stroke Aphasic Depression Questionnaire (SADQ-H) (Lincoln et al, 2000) was used as an index of behaviours indicative of depressed mood was completed by the allocated named nurse. Those patients who were not classified as aphasic completed a further set of assessments with the researcher. These were the Recovery Locus of Control (RLOC) (Partridge & Johnston, 1989) as a measure of locus of control, the Brief COPE (Carver, 1997) to assess coping strategies, the Beck Depression Inventory II (BDI-II) (Beck et al, 1996) for depressed mood, the Stroke Cognitions Questionnaire to evaluate positive and negative cognitions, and the Hospital Anxiety and Depression scale (HADS) (Zigmond & Snaith, 1983) as indices of distress, anxiety and depression. Details of the assessments and administration are provided along

with details of why these assessments were chosen for this study. Copies of the assessments may be found in Appendix 2.

Background and demographic information was recorded from hospital medical notes. The patient's date of birth, date of stroke, Bamford stroke classification, employment status, marital status and living arrangements were recorded. For patients who were retired or unemployed at the time of their stroke the researcher asked the patient or carer their most recent occupation. If employment status, marital status or living arrangements were not recorded in the medical notes then these details were obtained from the patient and/or carer. At follow-up employment status and living arrangements were checked again as these may have changed since the patient was in hospital. The researcher recorded from the medical notes whether the patient was receiving antidepressant medication. It was also documented whether the patient had had a previous stroke(s) as this was been suggested as a risk factor for distress in some studies identified in the literature review. The medical notes were also examined to determine whether the patient had previously received treatment for depression. Although this is a crude method of assessing depression history due to possible inconsistencies in the level of detail in medical records, G.P. records may be subject to similar criticism and reports from patients or carers may not have been reliable.

All patients were reassessed at six months after stroke. Patients were contacted by telephone to arrange follow-up assessments. Patients who could not be contacted by phone were contacted in writing. All patients who agreed to be reassessed at follow-up were visited by the researcher at their place of residence. At follow-up patients

were reassessed on the same battery of tests that were used at baseline. The Barthel Index was completed with the patient (or carer if the patient was aphasic) and the SADQ-H was completed by a carer/relative. In addition, the Extended Activities of Daily Living Scale (EADL) to assess independence in activities that extend beyond basic self-care was completed with all patients (with assistance from carer/relative for aphasic patients). Also at the follow up assessment, those patients who were not aphasic also completed the Significant Others Scale (Power et al, 1988) as an index of social support. The assessment battery for aphasic patients took between about 20 to 30 minutes to complete, and the full assessment battery for non-aphasic patients took between about 45 to 90 minutes to complete. For some patients the full assessment battery was administered over two sessions when patients were in hospital if the patient became tired or asked for it to be completed at a second visit. If the assessment was completed over two sessions then the second part of the assessment was completed within 24 hours of the first part of the assessment.

4.3 Results

4.3.1 Plan of analysis

The overall aim of the statistical analysis was to determine which factors or combination of factors that were assessed were significantly related to emotional distress at baseline and at follow up, and also to identify which baseline factors predicted distress at follow up. Separate models were tested for the whole sample (both patients with and without aphasia) and only for those without aphasia, as this latter group were able to complete a more detailed battery of assessments.

Demographic and background information was described using means (and standard deviation) for continuous data and frequencies and percentages for categorical data. Pairwise deletion of missing values was used in SPSS, whereby the case containing a missing value on scale Z were only excluded from analyses involving scale Z, but the case was included in all other analyses for which complete data was provided. This was appropriate as there was very little missing data. The alternative to this was to use listwise deletion in which the case is excluded from all analyses, however this option was not considered appropriate as it would have decreased the sample size for the analyses. Missing values could have been replaced with the mean value for the sample, but this would have biased scores towards the mean.

To examine which factors were significantly related to distress three main analyses were conducted. These were conducted firstly for the whole sample and secondly for patients without aphasia.

1. Baseline predictors of distress at baseline: to identify factors associated with distress at baseline, distress scores were compared for categorical variables (e.g. male and female). Independent samples t-tests were used to compare means for categorical variables with two groups and one-way ANOVAs were used for categorical variables with more than two groups. Pearson's correlations were conducted between continuous variables and distress scores to examine which factors were significantly associated with distress. To identify which factors were significant predictors of distress at baseline the variables that were significantly associated with distress were entered into multiple linear regression.
2. Follow up predictors of distress at follow up: the analyses conducted in step 1 were repeated with follow up variables and follow up distress scores.
3. Baseline predictors of distress at follow up: the analyses conducted in step 1 were repeated with baseline variables and follow up distress scores.

Data was analysed using SPSS for Windows version 11.5. Justifications for the use of parametric statistics will be discussed prior to reporting the results of the analyses.

Justification for parametric analysis

Parametric tests such as t-tests, ANOVA, Pearson's correlation and linear regression assume data is normally distributed and groups have homogeneity of variance. They also require data to be measured on an interval level scale in which the distance between adjacent values are equal. However, assessments used in clinical and psychological research typically use ordinal (Likert) ranking scales, whereby there is a hierarchical relationship between items so that they can be put into rank order, but the magnitude of difference between levels may not be equal. Ordinal scales are conducive to violating the assumption of normality due to their restrictive range

(Nanna & Sawilowsky, 1998). However, naturally occurring normal distributions are rare (Dunlap, Burke, & Greer, 1995). For data that do not meet the assumptions of parametric tests non parametric tests can be used, such as Mann-Whitney, Wilcoxon and Spearman's rank as these do not make assumptions about the distribution of the data.

There is disagreement in the literature as to whether ordinal scales can be treated as interval as there is a 'fuzzy line' between what can definitely be called 'ordinal' and 'interval' (Miles & Shelvin, 2001). Stevens (1946) proposed a relationship between measurement scales and statistical procedures, meaning that variables have qualities that determine which tests can be used on them. In contrast, Lord (1953) argued that there is no such relationship and that 'the numbers do not know where they came from'; therefore parametric statistics can be used with ordinal data. Miles and Shelvin (2001) noted that if we only used regression on truly interval or ratio data then we would rarely use the technique, suggesting that a more liberal approach could be taken. The assessments used in the present study were treated as interval level data as if a stricter interpretation was taken and data was treated as ordinal then this would have limited the analyses that could have been used. This followed the recommendation of Lord (1953) and was in accordance with a majority of studies which used the parametric analysis of multiple linear regression to explore factors associated with emotional distress after stroke (Berg et al, 2003; Cassidy et al, 2004; Dennis et al, 2000; Herrmann et al, 1998; Hosking et al, 2000; King et al, 2002; Spencer et al, 1995), therefore enabling comparisons with previous research.

Distributions of variables were also considered. Data that is skewed can be transformed (e.g. square root, reciprocal, log) to normalise the distribution. There are no consistent criteria on what level of skew is problematic and guidelines for when to transform data are mixed (Norris & Aroian, 2004). Also, the statistical test is conducted on transformed data, but the p value is reported for a null hypothesis based on untransformed data (Rascati, Smith, & Neilands, 2001). Norris and Aroian (2004) found no benefit of transforming skewed data on reliability statistics (Cronbach's alpha and Pearson's correlation). When deciding whether to transform data the researcher should consider the severity of skew and the loss in interpretation that occurs when data becomes a step removed from the original measurement. An alternative to transformation is the bootstrap technique. This simulates repeated random sampling and analyses samples that have been randomly selected from the observed data (Rascati et al, 2001). However the bootstrap is a complex manipulation and few software packages currently exist to perform this technique comprehensively.

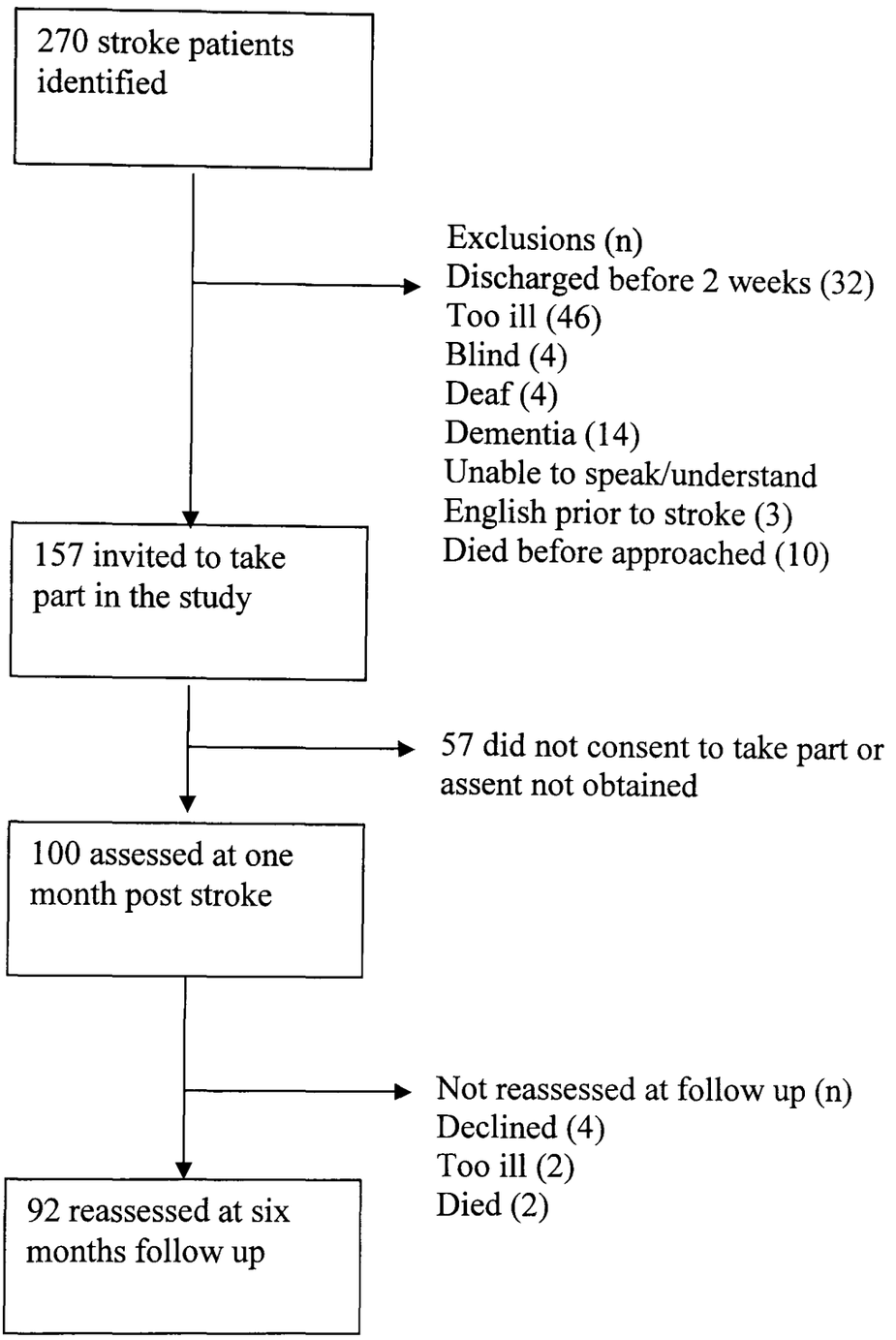
Townend (2004) also used the HADS total score as a measure of distress and argued that it was not accurate to normalise distress as theory and practice expect it to be positively skewed. Dichotomising the distress variable would have violated the linearity assumption of multiple linear regression and would have resulted in a loss of detail. The present study was also interested in distress as a continuous variable, rather than a categorical variable, therefore it was not appropriate to dichotomise the distress variable.

In deciding whether to employ parametric tests on data that do not meet the assumptions the researcher should consider the *robustness* of a test, that is, the ability of the test to remain valid when underlying assumptions are violated (Nanna & Sawilowsky, 1998). Some authors have suggested that parametric tests are robust and can be used (see Nanna & Sawilowsky, 1998 for a review). Parametric analyses were used in the present study as there is evidence that parametric tests are reasonably robust to Type I and Type II errors for non-normal distributions if the sample size is large and tests are two-tailed (Sawilowsky & Blair, 1992). It was not appropriate to transform data as this can inflate correlations (Dunlap et al, 1995) and would have made interpretation more difficult.

4.3.2 Patient recruitment

During the time frame of the study 270 patients were identified on the stroke wards in the four hospitals and considered for inclusion in the study. Figure 4.1 summarises the flow of patients and reasons for exclusion from the study. Of the 270 patients, 113 (41.85%) were not invited to take part in the study because they did not meet the inclusion criteria. One hundred and fifty seven patients (58.15%) met the inclusion criteria and were invited to take part in the study. Of these 157 patients, 57 (36.31%) did not consent to take part or assent was not obtained. One hundred patients (63.69%) who met the inclusion criteria gave consent or assent was obtained from a carer or relative to participate in the study. Forty two patients were recruited from QMC, 33 from Nottingham City Hospital, 15 from Mansfield Community Hospital and 10 from the DRI.

Figure 4.1 Flow chart of recruitment



4.3.3 Patient characteristics

Of the 100 patients recruited 51 were men. The mean age of patients was 70.15 years (sd=9.38), with age ranging between 44 and 86 years. A chi-square was used to compare the gender of patients recruited to the study with those who did not consent to take part and age was compared using a between groups t-test. The results are summarised in Table 4.2. Patients who declined to participate in the study were

significantly older than those who consented to take part. There was no significant difference in the gender of patients who did or did not consent to take part. No other information was collected on patients who did not consent to participate in the study.

Table 4.2. Gender and age of patients recruited and those who did not consent to take part

	Patients recruited to the study (n=100)	**Patients who did not consent to take part (n=57)**	**Comparison p value**
Age Mean SD	 70.15 9.38	 84.11 6.67	 <.001
Gender Male (n) Female (n)	 51 49	 37 40	 .957

SD= standard deviation

Patients were assessed between 18 and 47 days post-stroke, with assessments taking place at a mean of 30.87 days post-stroke (SD=8.29). Therefore most assessments were at approximately one month post-stroke. Demographic characteristics of the sample included in the study are summarised in Table 4.3 (percentages not shown as n=100). Most patients were married (57) and were living with their spouse. Eighty four patients were retired when they had their stroke, the remainder were employed at the time of stroke.

Male participants were more likely to be married and therefore living with a spouse, while female participants were equally likely to be married (and so living with a spouse) or widowed (and usually living alone). Men were slightly younger (mean

68.57 years, SD=9.84) than the females (mean 71.80 years, SD=8.67), but this difference was not significant (t_{98}= -1.73, p=.085).

Relevant medical history as documented in the medical notes is summarised in Table 4.4. A history of depression as documented in the medical notes was uncommon and was only recorded for four of the patients. The prescription of antidepressant drugs was also uncommon for patients at baseline and was only recorded for seven of the patients. Fourteen patients had suffered a previous stroke.

Table 4.3. Demographic characteristics of the sample

Characteristic	Total n	Men	Women
Marital status			
Married	57	34	23
Divorced	3	1	2
Widowed	35	13	22
Single	5	3	2
Living arrangements			
With spouse	57	34	23
With other family member	4	0	4
Alone	39	17	22
Employment status at time of stroke			
Employed	16	10	6
Retired	84	41	43
Unemployed	0	0	0

Table 4.4. Relevant medical history of the sample documented in medical notes

Medical condition	n
Previous depression	
Yes	96
No	4
Previous stroke	
Yes	14
No	86
Prescribed antidepressant at time of assessment	
Yes	7
No	93

Stroke characteristics

Stroke characteristics were described using the Bamford classification, side of weakness and side of lesion. These are summarised in Table 4.5. A majority of patients were classified as PACS while POCS was least common. The Bamford classification was not documented for five patients. Right hemisphere lesion was more common than a left hemisphere lesion, and lesion side was unknown or not able to be determined as definitely right hemisphere or left hemisphere from the medical notes for seven patients.

Table 4.5. Stroke characteristics

Stroke characteristics	n (%)
Bamford classification (n=95)	
TACS	17 (17.89%)
PACS	45 (47.37%)
POCS	11 (11.58%)
LACS	22 (23.16%)
Side of weakness (n=100)	
Left	44
Right	51
Bilateral	4
No weakness	1
Side of lesion (n=93)	
Left	42 (45.16%)
Right	51 (54.84%)

4.3.4 Assessments of emotional distress at baseline

All 100 patients completed the VASES and the VAMS. Seventy nine patients completed the HADS and the BDI-II. The remaining 21 did not complete the HADS and BDI-II as they were classified as aphasic by the Sheffield Screening Test. Ward staff completed the SADQ-H for 89 of the patients. The remaining 11 SADQ-H questionnaires were not returned to the researcher.

Descriptive statistics for the depression measures of emotional distress are shown in Table 4.6.

Table 4.6. Descriptive statistics for measures of emotional distress

Measure	n	Range of possible scores	Range	Mean	SD
VASES*	100	10-50	19-50	38.85	0.64
VASES-D*	100	11-55	21-55	42.77	7.23
VAMS	100	0-800	7-643	260.90	123.91
VAMS-HE	100	0-600	0-559	157.21	120.33
SADQ-H	89	0-63	0-39	12.33	8.49
HADS-depression	79	0-21	0-12	3.90	3.00
HADS-anxiety	79	0-21	0-11	4.37	3.11
HADS-total	79	0-42	0-19	8.27	5.33
BDI-II	79	0-63	0-34	9.70	6.98

VASES-D VASES total including depression item
VAMS–HE VAMS total with happy and energetic items removed
SD=standard deviation
*Higher score indicated lower distress

The mean score on the VASES-D was slightly higher than the half-way score indicating that scores tended towards low levels of distress. The VAMS-HE scores were positively skewed, with most scores being low (indicating better mood) and few patients having higher scores, although the standard deviation was large. The mean

SADQ-H scores were also low. Mean scores on the HADS total and subscale scores and the BDI-II were both reasonably low and were positively skewed, with few patients scoring at the extreme high end of the scale.

The Kolmogorov-Smirnov test for normality was conducted on the measures of emotional distress. The VASES-D total score ($z=.084$, $p=.080$) and HADS distress score ($z=.100$, $p=.065$) did not significantly differ from the normal distribution. The VAMS-HE ($z=.123$, $p=.001$), HADS depression subscale ($z=.167$, $p<.001$), anxiety subscale ($z=.131$, $p=.014$), SADQ-H ($z=.109$, $p=.011$) and BDI-II ($z=.160$, $p<.001$) were significantly different from the normal distribution.

In order to further examine the distributions, z skew values were calculated for each scale, as this is more informative than raw skew. z skew is calculated using (S – 0) / SE skew (where S is skew and SE skew is standard error of the skew), and values above 1.96 are significantly different from that expected by a normal distribution ($p<.05$) and may be problematic (Field, 2000). The z skew for the scales are shown Table 4.7.

Table 4.7. z skew for measures of emotional distress

Scale	z skew
VASES-D	-1.453
VAMS-HE	4.900
SADQ-H	1.545
HADS-D	2.845
HADS-A	1.074
HADS-total	.697
BDI-II	4.005

The z skew values show that the skew of the VAMS-HE, HADS-D and BDI-II were significantly different ($p<.05$) from that expected from a normal distribution as they were $>|1.96|$. As the HADS total score, VASES-D and VAMS-HE were not significantly different from the normal distribution these were used as the dependent variables in analyses exploring factors associated with distress and it was appropriate to use parametric statistics as these scales were not significantly skewed.

Comparison between aphasic and non aphasic patients on distress measures at baseline

Twenty one patients were classified as 'aphasic' using the Sheffield Screening Test. The mean age of aphasic patients (71.25 years) was not significantly different from non aphasic patients (69.86 years) (t_{98}-.596, p=.553). Twelve men and nine women were aphasic so gender was not significantly associated with aphasia (χ^2=.401, p=.526).

Table 4.8 shows distress scores for aphasic and non aphasic patients. Scores between the two groups were compared using Independent Samples t-tests. Aphasic patients scored significantly higher than non aphasic patients on the VAMS-HE and significantly lower on the VASES-D indicating that aphasic patients were more distressed. SADQ-H scores did not differ between those with and without aphasia.

Table 4.8. Comparison between aphasic and non aphasic patients on distress scores

Scale	Aphasic (n=21)		Non aphasic (n=79)		Comparison p value
	Mean	SD	Mean	SD	
VASES-D	39.29	7.83	43.65	7.25	.018*
VAMS-HE	236.95	138.11	136.01	106.40	<.001***
SADQ-H	10.85 (n=20)	9.96	12.75 (n=69)	8.04	.380

***p≤.001 *p≤.05

Classification of depression baseline

SADQ-H

SADQ scores were available for 89 of the 100 patients. A cut-off of 17/18 was used on the SADQ to classify patients as depressed (Bennett et al, in press). Twenty nine of the 89 patients (32.58%) for whom the SADQ-H were returned were classified as depressed.

HADS

A cut-off of 6/7 was used to categorise patients as 'depressed' and 'anxious' on the depression and anxiety subscales of the HADS (O'Rourke et al, 1998). Seventeen of the 79 patients were identified as depressed (21.52%) and 20 anxious 25.32%.

A cut-off of 10/11 was recommended on the HADS total score to screen for DSM-IV major depression in stroke (Aben et al, 2002). Using this cut-off, 31 patients (39.24%) were depressed.

BDI-II

A cut-off of 13 was used on the BDI-II to classify depression (Beck et al, 1996). Twenty (25.32%) of the 79 patients were classified as depressed.

4.3.5 Description of assessment scores at baseline

Table 4.9 shows the descriptive statistics for the remaining assessment scales. Sheffield Screening Test scores were negatively skewed (skew=-.156), with most patients scoring high. Data was not available to explore whether patients who did not participate in the study were more likely to have aphasia. Barthel Index scores approximated a normal distribution (skew=-.20). Most patients scored around 11, and few scored very low or independent. SCQR total scores were positively skewed (skew=1.02), with scores generally low. RLOC scores were generally negatively skewed (skew=-.780) and the mean indicates patients tended to have an internally oriented locus of control. Few patients scored very low on the adaptive subscale (skew=-.217) of the Brief COPE with most scores clustered around the middle of the range. Maladaptive coping scores were low (skew=.579). The alcohol subscale was removed from the Brief COPE as no patients reported this strategy. The religion subscale was also removed as only seven patients reported using this strategy.

Scores on the Sheffield Screening Test, pre-stroke Barthel, pre-stroke EADL and the SCQR were significantly different from the normal distribution ($p<.05$). The skew for the remaining variables was not significant ($p>.05$). The Sheffield Screening Test could have been dichotomised into 'aphasic' and 'not aphasic' but this would have resulted in a loss of detail. Also, it is of interest to consider severity of language impairment rather than the presence of aphasia as this has not been explored in previous research. As outlined previously, it was not considered appropriate to

transform skewed data and parametric statistics are reasonable robust for non-normal distributions (Sawilowsky & Blair, 1992).

Table 4.9 Description of baseline assessment scores

Measure	n	Range of possible scores	Range	Mean	SD
Sheffield Screening Test total*	100	0-20	4-20	17.11	3.58
Receptive subscale*	100	0-9	2-10	7.55	1.49
Expressive subscale*	100	0-11	0-11	9.56	2.58
Barthel Index*	100	0-20	2-20	11.62	4.69
SCQR total	79	0-63	0-48	14.81	10.09
SCQR positive cognitions total	79	0-27	0-23	5.18	4.72
SCQR negative cognitions total	79	0-36	0-29	9.63	6.90
RLOC*	79	9-45	20-43	35.53	4.71
COPE adaptive coping*	79	14-56	27-51	41.29	6.05
COPE maladaptive coping	79	10-40	10-30	17.72	5.50
Pre-stroke Barthel	100	0-20	13-20	18	4.51
Pre-stroke EADL	100	0-66	50-66	58	10.22

SCQR Stroke Cognitions Questionnaire Revised
RLOC Recovery Locus of Control Scale
* Higher score is more positive

Correlations between measures of emotional distress at baseline

Correlations were calculated between the measures of emotional distress to examine whether there was any relationship between the self-report, visual analogue scales and the observer rated assessment. This also provided information about multicollinearity. Correlations above 0.80 or 0.90 indicate multicollinearity between measures (Field, 2000). Correlations were calculated using Pearson's correlation and are summarised in Table 4.10. The use of parametric statistics was justified at the outline of the Results chapter. However, as some of the scales (VAMS-HE and SADQ-H) were significantly skewed, correlations were also calculated using Spearman's correlation (non parametric) and significant correlations remained significant.

<u>All patients:</u>

The VASES and VAMS were significantly highly correlated, however this was < |0.80|, suggesting that there is not multicollinearity. The VASES-D was significantly correlated with the SADQ-H, however, the correlation between the VAMS-HE and SADQ-H was extremely low (r=.001).

<u>Non aphasic patients:</u>

The HADS anxiety and depression subscales were significantly highly correlated with one another and with the HADS total score. This indicates a large overlap between theses scales, and supports the use of the HADS total as a distress score (Townend, 2004).

The HADS-D and HADS-total scores were significantly highly correlated with the VAMS-HE, VASES-D and SADQ-H, providing evidence for the concurrent validity

of the VAMS-HE, VASES-D and SADQ-H as measures of mood. The HADS-A subscale was significantly correlated with the VAMS-HE and VASES-D, but not with the SADQ-H. None of the correlations were >|0.80| therefore there was no evidence of multicollinearity.

Correlations between the BDI-II, SCQR and the visual analogue and observer ratings of mood were highly significant, with the exception of the VAMS-HE not correlating the SCQR. None of the correlations were above 0.80. The finding that the visual analogue scales (VASMS-HE and VASES-D) and observer rating of mood (SADQ-H) were correlated with the BDI-II provides further evidence for the concurrent validity of the scales as measures of mood.

The self-report measures of emotional distress were all significantly correlated, as expected. The correlation between the HADS-D and BDI-II was >0.80 indicating multicollinearity. The correlation between the HADS-D and SCQR total score was also >0.80 which indicates overlap between the depression and the frequency of negative cognitions.

Table 4.10. Correlations between measures of emotional distress

	1. VAMS-HE		2. VASES-D		3. SADQ-H		4. HADS-A		5. HADS-D		6. HADS total		7. BDI-II		8. SCQR total	
	r	p	r	p	r	p	r	p	r	p	r	p	r	p	r	p
1.			-.462	<.001	.001	.989	.368	.001	.280	.013	.326	.003	.313	.005	.175	.124
2.					.418	<.001	-.517	<.001	-.529	<.001	-.601	<.001	-.443	<.001	-.486	<.001
3.							.214	.077	.563	<.001	.444	<.001	.459	<.001	.464	<.001
4.									.519	<.001	.877	<.001	.580	<.001	.546	<.001
5.											.866	<.001	.790	<.001	.826	<.001
6.													.793	<.001	.784	<.001
7.															.717	<.001
8.																

r Pearson's correlation coefficient

p Probability

4.3.6 Associations with emotional distress at baseline– whole sample

Prior to conducting multiple linear regression to identify predictors of emotional distress at baseline, analyses were carried out to identify which variables were related to distress. Analyses were conducted on the whole sample, and further analyses then performed on the non aphasic patients who completed additional measures.

To decrease the number of statistical tests performed and reduce the chance of Type I error, analyses were carried out on only one visual analogue scale. The VASES-D was chosen in preference to the VAMS-HE as the internal consistency for the VASES-D is higher than the VAMS-HE (Bennett et al, in press) and the VASES-D was normally distributed. The SADQ-H was included as an observer rating of distress.

Independent sample t-tests were performed for categorical variables with two groups. One-way ANOVAs were performed to calculate whether there were any differences between categorical variables on the VASES-D and SADQ-H for categorical variables with more than two groups. Levene's test for homogeneity of variance was not violated for any of the comparisons. Pearson's correlations were calculated for continuous variables.

Comparisons between categorical variables are summarised in Table 4.11.

Table 4.11. Comparison between VASES-D and SADQ scores for categorical variables

Characteristic	VASES-D			SADQ-H		
	Mean	SD	p	Mean	SD	p
Gender						
Male	43.65	8.09	.229	13.38	8.90	.216
Female	43.65	6.92		11.14	7.94	
Marital status						
Single	36.00	9.67	.071	9.00	7.28	.351
Married	42.70	7.15		13.42	8.04	
Divorced	49.00	6.00		3.67	3.32	
Widowed	43.20	7.63		11.94	9.29	
Living arrangements						
Alone	43.18	8.00	.395	11.47	9.09	.351
With spouse	42.77	7.10		13.25	8.05	
With son/daughter	37.75	9.74		7.75	7.75	
Employment status						
Employed	41.63	9.89	.618	10.69	9.54	.456
Retired	42.94	7.07		12.61	8.33	
Previous depression						
Yes	43.75	4.99	.784	17.50	8.66	.214
No	42.68	7.65		12.08	8.45	
Previous stroke						
Yes	42.64	7.80	.964	12.45	10.29	.958
No	42.74	7.55		12.31	8.29	
Side of lesion						
Left	41.68	7.52	.318	12.28	8.97	.992
Right	43.46	7.70		12.26	8.26	
Bamford classification						
TACS	39.47	9.13	.158	13.53	11.58	.702
PACS	44.33	7.34		11.45	7.87	
POCS	42.82	7.00		10.82	8.00	
LACS	13.59	6.65		13.59	7.36	

p Probability, SD=standard deviation

Distress scores were unrelated to gender. VASES-D scores were lowest in patients who were single but this was not significant. There was no significant difference between SADQ-H scores for marital status. Only three patients were divorced and five were single. Therefore, categories were combined to compare VASES-D scores for patients who were married (mean 42.70, SD=7.15), with those divorced, widowed or single (mean 42.77 SD=8.13) but no significant difference was found (t_{98}=-.046, p=.963). Similarly, SADQ-H scores were not significantly different between patients who were married (mean 13.42 SD=8.04) and those divorced, single or widowed (mean 10.92, SD=8.93) (t_{87}=1.38, p=.170). Employment status was unrelated to distress. Therefore, VASES-D and SADQ-H scores were not associated with marital status, living arrangements or employment status.

Only four patients had a history of depression documented in hospital medical notes. VASES-D and SADQ-H scores did not significantly differ between patients with a history of depression and those without a history of depression. Also, VASES-D and SADQ-H scores were not significantly different between patients who had had a previous stroke compared with those who had not had a previous stroke.

VASES-D scores and SADQ-H scores did not significantly differ between patients with a right sided lesion and patients with a left sided lesion. VASES-D scores were lower for patients classified as TACS compared with PACS, POCS and LACS, but this difference was not significant SADQ-H scores were higher for TACS and LACS patients compared with PACS and POCS patients, but this not significant. Correlations between continuous variables and VASES-D and SADQ-H are summarised in Table 4.12.

Table 4.12. Correlations with VASES-D and SADQ scores

	VASES-D		SADQ-H	
	r	p	r	p
Age	.121	.233	.032	.765
Sheffield Screening Test total	.439	<.001***	-.140	.191
Sheffield Screening Test receptive	.329	.001***	.106	.322
Sheffield Screening Test expressive	.370	<.001***	.026	.806
Barthel Index	.371	<.001***	-.233	.028*
Pre-stroke Barthel Index	.205	.198	-.101	.411
Pre-stroke EADL	.178	.223	-.130	.350

r Pearson's correlation

p probability level

*** $p \leq .001$, * $p \leq .05$

Age was not significantly correlated with distress. Patients who scored higher on the Sheffield Screening Test total and receptive and expressive subscale (indicating absence of communication impairment) had higher scores on the VASES-D (indicating less distress), but communication impairment was unrelated to the SADQ-H. Patients who were more independent on the Barthel Index scored higher on the VASES-D and lower on the SADQ-H, indicating less distress. Pre-stroke activity levels were not significantly correlated with distress.

Assumptions of linear regression

Heuristics for the sample size required for regression analysis vary in the literature. Tabachnick and Fiddell (1996) recommended a ratio of cases to independent variables of $N \geq 50 + 8m$ (where m=number of independent variables). Other researchers recommend between 10 (Howell, 1997) and 15 (Field, 2000) subjects per predictor. Following this, with a sample size of 100 in the present study, between six and 10 predictor variables can be included in the regression.

Variables being correlated should be normally distributed and for every value of X, the distribution of Y scores must have approximate equal variability. (homoscedasticity). The distribution of scores has been considered earlier in this chapter. The dependent distress variables were normally distributed. As previously noted, the Sheffield Screening Test was not normally distributed but as the skew for this variable was <2 this should not affect parameter estimates (Miles & Shelvin, 2001). The relationship between X and Y must be linear for continuous variables and this was tested by examining correlations between the variables, only those that were significantly correlated with distress were included in the regression.

Distributions were checked for outliers (cases that differ substantially from the trend of the data) by examining graphs, Mahalanobis distance and leverage. Extreme values were compared against hard copies of the data to check there was no error in data entry. Data was also checked for multicollinearity as this can make a Type II error more likely and limit the size of R due to shared variance between predictors (Field, 2000). Collinearity was assessed by examining correlation coefficients between predictor variables. No predictor variables were correlated >.80.

Forward entry regression was used whereby the model starts empty and the variable with the highest significant standardised beta is added to the equation. The variable with the next highest standardised beta is then added to see whether it is significant. This process continues until no further variables are significant. This method was used as it identifies the variables independently associated with the outcome variable and which explains the greater proportion of variance in the outcome (Dennis et al, 2000).

4.3.7 Factors predicting emotional distress at baseline – whole sample

Regression model for VASES-D at baseline

VASES

Multiple linear regression was used to evaluate a model for the prediction of baseline VASES-D scores. The variables significantly associated with VASES-D scores were the Sheffield Screening Test and Barthel Index. Both the receptive and expressive subscales of the Sheffield were entered into the regression model rather than the total to determine whether the nature of the communication impairment was relevant. These three variables (Barthel Index, receptive communication and expressive communication) were entered into the regression as independent variables. The results of the regression are summarised in Table 4.13.

Table 4.13. Regression model for baseline VASES-D scores.

	B (95% CI)	SE	Standardised B	t	Significance of t	Partial correlatio
Sheffield Expressive	.875 (.416-1.494)	.242	.336	3.52	<.001***	.345
Barthel Index	.377 (.146-.741)	.133	.263	2.84	.006	.277
Sheffield Receptive			.132	1.28	.204	.130

CI confidence interval
SE standard error
*** $p \leq .001$

Sheffield expressive scores and Barthel Index scores were significant predictors of VASES-D. Sheffield receptive scores were not a significant predictor and were removed from the model. The model containing the Sheffield expressive subscale and the Barthel Index was highly significant ($F_{2,97}=14.83$, $p<.001$). This means that for a one unit increase in expressive scores on the Sheffield Screening Test (less communication impairment) there was a .875 increase in scores on the VASES-D (less distress) when the effect of the Barthel Index was held constant. Similarly, for a one unit increase in the Barthel Index (greater independence in ADL) there was a .377 increase in VASES-D scores, when the effect of expressive communication was held constant. The R^2 for the model was .236 which means the model accounted for almost one quarter of the variance in VASES-D scores.

Regression model for SADQ-H at baseline

The Barthel Index was significantly correlated with the SADQ-H. Linear regression was carried out to evaluate a model of baseline SADQ-H scores using the Barthel Index as the predictor variable. Forward regression was conducted. The results of the regression are shown in Table 4.14.

Table 4.14 Regression model for baseline SADQ-H scores

	B	SE	Standardised B	t	Significance of t	Partial correlation
Barthel Index	-.410 (95% CI)	.183	-.233	-.238	.028	-.233

CI confidence interval
SE standard error

Barthel Index scores were significant predictor of baseline SADQ-H scores. The regression model was significant ($F_{1,87}$=5.01, p=.028). For each one unit increase in the Barthel Index (greater independence in ADL) there was a .410 decrease in SADQ scores (less distress). The R^2 for the model was .054, meaning that Barthel Index scores only accounted for about 5% of the variance in SADQ-H scores.

4.3.8 Factors relating to emotional distress at baseline – non aphasic patients

The HADS total score was used as the present study was interested in distress and the HADS total score was normally distributed. One-way ANOVAs were performed to calculate whether there were any differences in HADS total scores for categorical variables with more than two groups. Independent sample t-tests were performed for categorical variables with two groups. Levene's test for homogeneity of variance was

not violated for any of the comparisons. Pearson's correlations were calculated for continuous variables.

BDI-II scores and SCQR scores were not entered into the regression analysis as they were highly correlated with the HADS-total score (r values of .793 and .784 respectively), indicating multicollinearity as this is close to .80. The BDI-II is a measure of depression therefore it would therefore not be informative to include it in the regression. Also, the SADQ was not included as it was also a measure of mood.

Seventy nine patients were not aphasic and were included in the analysis, except for variables where there were missing values and pairwise deletion was used. Comparisons between distress scores for categorical variables are summarised in Table 4.15.

Table 4.15. Comparisons between HADS distress scores for categorical variables.

Characteristic	HADS distress		
	Mean	SD	p
Gender			
Male	8.56	5.76	.626
Female	7.89	4.93	
Marital status			
Single	9.75	7.75	.503
Married	8.17	5.72	
Divorced	3.00	4.24	
Widowed	8.62	4.67	
Living arrangements			
Alone	8.61	4.72	.471
With spouse	8.17	5.71	
With son/daughter	2.00	n/a (n=1)	
Employment status			
Employed	7.75	5.94	.718
Retired	8.36	5.25	
History of depression			
Yes	14.00	5.66	.124
No	8.12	5.27	
Previous stroke			
Yes	9.64	5.70	.361
No	8.04	5.28	
Side of lesion			
Left	7.88	5.09	.864
Right	8.11	5.45	
Bamford classification			
TACS	15.25	3.40	.018
PACS	7.38	5.50	
POCS	5.33	4.81	
LACS	8.31	4.19	

p Probability, SD=standard deviation

Distress scores were slightly higher for men but this difference was not significant. Distress scores were not significantly different between patients who were married, single, divorced or widowed. Only two patients were divorced and four were single. Categories were combined to compare HADS distress scores for patients who were married (mean 8.17, SD=5.72) with those who were single, divorced or widowed (mean 8.40, SD=4.79) and no significant difference was found (t_{77}=-.192, p=.848). Distress scores were not significantly different according to living arrangements When the patient living with their son/daughter was removed from the analysis there remained no significant difference between patients living alone and those living with a spouse (t_{78}=-.192, p=.848). Distress scores were not significantly different between patients employed and those retired at the time of stroke HADS distress scores were therefore not associated with marital status, living arrangements or employment status.

HADS distress scores were higher for patients with a history of depression and for those who had had a previous stroke but these differences were not significant. Distress scores were slightly higher for patients who had a right sided lesion than those with a left sided lesion but this difference was not significant. HADS distress scores were higher for patients classified as TACS compared with PACS, POCS and LACS and the overall difference was significant. Tukey's post hoc test showed that the difference was significant between TACS and PACS (p=0.026), TACS and POCS (p=0.021), and TACS and LACS (p=0.048).

Correlations between continuous variables and the HADS total score are summarised in Table 4.16.

Table 4.16. Baseline correlations with HADS total scores

	HADS total	
	r	p
Age	.039	.730
Sheffield Screening Test total	-.432	<.001***
Sheffield Screening Test receptive	-.217	.055
Sheffield Screening Test expressive	-.331	.003**
Barthel Index	-.506	<.001***
Pre-stroke Barthel	-.198	.105
Pre-stroke EADL	-.160	.134
RLOC	-.548	<.001***
Adaptive Coping	-.419	<.001***
Maladaptive Coping	.440	<.001***

r Pearson's correlation
p probability level
*** p≤.001, ** p≤.01 *p≤.05

Age was not significantly associated with distress. The Sheffield Screening Test total score and expressive scores were significantly associated with distress whereby less communication impairment was associated with lower distress. Barthel scores were significantly negatively correlated with HADS total scores which means that greater independence in ADL was associated with less distress. Adaptive coping was also significantly negatively correlated with distress score and there was a significant positive correlation between maladaptive coping strategies and distress.

RLOC scores significantly were positively correlated with adaptive coping (r=.524, p<.001) indicating that a more internal the locus of control is associated with adaptive coping. Partial correlations were carried out to explore this. RLOC and distress scores remained correlated when adaptive coping scores were controlled for

(r=-.453, p<.001). However, the correlation between adaptive coping and distress scores was no longer significant when RLOC scores were partialled out (r=-.185, p=.105). Similarly, RLOC scores were significantly negatively correlated with maladaptive coping (r=-.647, p<.001), such that an internal the locus of control is associated with less maladaptive coping. Partial correlations between RLOC and distress scores controlling for maladaptive coping scores showed that the correlation remained significant (r=-.385, p=.001). However, the correlation between maladaptive coping and distress was no longer significant when RLOC scores were controlled for (r=.132, p=.249). Coping scores were therefore not entered into the regression due to the shared variance with RLOC scores. This also reduced the number of variables entered into the regression.

4.3.9 Factors predicting emotional distress at baseline – non aphasic patients

Regression model for HADS distress scores at baseline

Forward linear regression was carried out to test a model predicting HADS distress scores. Barthel Index scores, RLOC scores and Sheffield Screening Test total scores and Bamford stroke classification were entered as predictor variables as these were all shown to have significant relationships with HADS distress scores. Regarding the Bamford classification, patients were coded as TACS or not TACS as patients who had a TACS had significantly greater distress than the other stroke types. Sheffield Screening Test total scored were entered rather than the subscale scores as all patients were not aphasic, therefore it was of interest to look at overall communication impairment. The results of the regression are shown in Table 4.17.

Table 4.17 Baseline regression with HADS total scores

	B (95% CI)	SE	Standard-ised B	t	Sig of t	Partial correlation
RLOC	-.415 (-.616- .215)	.100	-.368	-4.138	<.001	-.443
Sheffield total	-1.866 (-2.164-1.09)	.389	-.391	-4.799	<.001	-.498
Barthel Index	-.373 (-.580- -.166)	.104	-.391	-3.590	.001	-.394
TACS stroke	-.100			-1.193	.237	-.142

CI confidence interval
SE standard error

RLOC scores, Sheffield Screening Test total scores and Barthel Index scores were significant predictors of distress scores in the model. Bamford classification was not significant and was not included in the model. The final model was significant ($F_{3,70}$=28.02, p<.001). The R^2 for the model was .546 therefore it accounted for just over half of the variance in the HADS distress scores.

To check that the exclusion of adaptive and maladaptive coping from the analysis was correct, the regression was repeated including these, but both adaptive coping (t=-1.675, p=.098) and maladaptive coping (t=1.748, p=.085) were not significant predictors in the regression. However, as adaptive and maladaptive coping were correlated with distress scores prior to RLOC scores being controlled for this suggests there is a relationship between coping and recovery locus of control. It is possible that the relationship between coping and distress was mediated by recovery locus of control, as the correlation between coping and distress was not significant

when RLOC scores were partialled out. The prediction would be that adaptive coping had a positive influence on locus of control (i.e. more adaptive coping influences more internal locus of control) while maladaptive coping had a negative influence on locus of control (i.e. maladaptive coping influences a more external locus of control). Mediation implies that there is a causal chain. One source of bias that can occur in this chain is feedback, this is when the mediator (in this example, locus of control) is caused by the dependent variable (distress) (Baron & Kenny, 1986). However, the study in Chapter 3 assessed depression and locus of control and two time points and found that RLOC scores at baseline remained a significant predictor of depression at follow up when baseline depression scores on the BDI were also included in the analysis. This implied that RLOC scores were an independent predictor of depression and therefore it is predicted that in this mediation analysis that RLOC will be a mediator between coping and distress, with the direction of causation flowing from RLOC (the mediator) to distress (the dependent/outcome variable).

To test this proposed mediation, four steps must be satisfied (Baron & Kenny, 1986) where X is the predictor variable, Y is the outcome variable and M is the mediator variable:

1. Show that X a significant predictor of Y using regression
2. Show that X is a significant predictor of M using regression
3. Show that M is a significant predictor of Y when controlling for X. Tested by conducting multiple regression with X and M as predictor variables and Y as the outcome variable.
4. If M is a complete mediator of the relationship between X and Y, then the effect of X should become zero when controlling for M. If partial mediation exists then the effect will be reduced.

These conditions were tested for adaptive and maladaptive coping. X corresponds to adaptive coping, Y to distress and M to RLOC.

1. Show that adaptive coping is a predictor of distress using regression. Linear regression using HADS distress score as the dependent variable and adaptive coping as the predictor variable showed that B was -.369 (standardised β=-.419) which was significant at ($p<.001$). Condition 1 was satisfied.
2. Show adaptive coping is a predictor of RLOC using regression. Linear regression using RLOC as the dependent variable and adaptive coping as the predictor variable showed that B was .408 (standardised β =.524) which was significant ($p<.001$). Condition 2 was satisfied.
3. Show RLOC is a significant predictor of distress when controlling for adaptive coping. Multiple linear regression was conducted using RLOC and adaptive coping as predictors and HADS distress as the dependent variable. B coefficient for RLOC was -.620 (standardised β=-.548) which was significant at ($p<.001$). Condition 3 was satisfied.
4. For full mediation, the effect of adaptive coping on distress should be eliminated when RLOC is controlled for. Multiple linear regression in step 3 showed that the B coefficient for adaptive coping when controlling for RLOC was -.182 which was not significant ($p=.185$). Therefore partial mediation has occurred as although B has substantially reduced the coefficient is >0. The amount of mediation is calculated by the difference in the slopes in steps 1 and 4 (Miles & Shelvin, 2001). This is -.369 - -.182 = -.187.

There was therefore evidence that RLOC mediated the relationship between adaptive coping and distress, whereby an increase in adaptive coping was associated with an

increase in internality of locus of control, which in turn decreased distress. This is depicted in Figure 4.2.

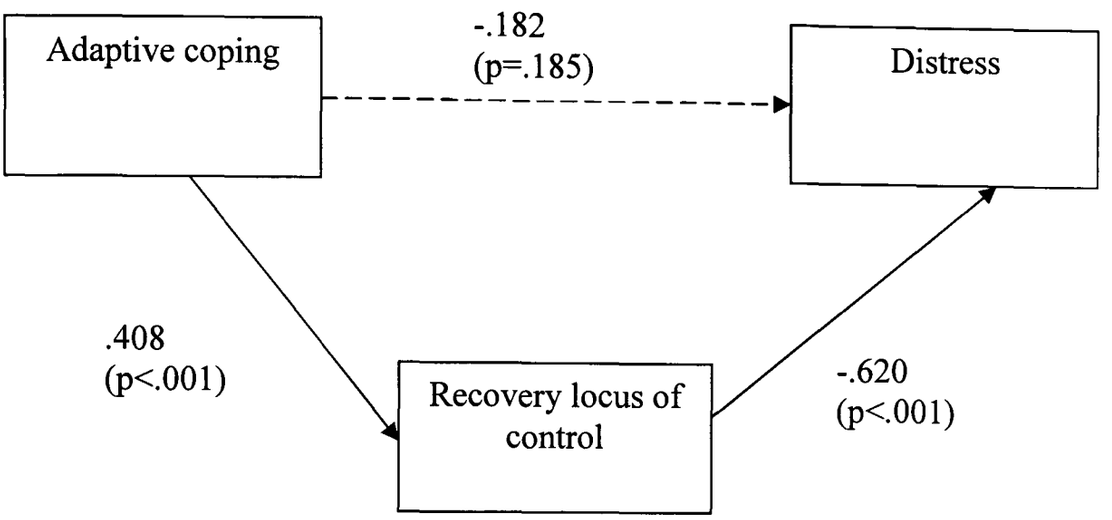


Fig 4.2. Relationship between adaptive coping and distress, mediated by recovery locus of control.

To test the significance of the mediated effect, the z score of the mediated effect was calculated by dividing the mediated effect by its standard error. If z is >1.96 the effect is significant at p<.05 (Frazier, Tix, & Barron, 2004). The formula for the standard error of the mediated effect is $\sqrt{b^2sa^2 + a^2sb^2 + sa^2sb^2}$, where a (path between X and M) and b (path between M and Y) are the unstandardised regression coefficients and sa and sb are the standard error of these coefficients (Baron & Kenny, 1986). Unstandardised regression coefficients were used as recommended by Frazier et al (2004). Standardised coefficients would have taken into account differences in units of measurement across assessments. However, the test of the significance of the mediated effect is calculated using a z score which standardises the measurement. The z score of the mediated effect was –3.650. As this is > |1.96| the mediated effect was significant (p<.05).

The procedure was repeated for maladaptive coping.

1. Linear regression using maladaptive coping as a predictor of distress produced a B coefficient of .426 (standardised β=.440) which was significant (p<.001). Condition 1 was satisfied.
2. Linear regression using maladaptive coping as a predictor of RLOC produced a B coefficient of -.556 (standardised β=-.649) which was significant (p<.001). Condition 2 was satisfied.
3. Multiple linear regression was conducted using maladaptive coping and RLOC as predictors and distress as the dependent variable. The B coefficient for RLOC was -.620 (standardised β=-.548) which was significant (p<.001). Condition 3 was satisfied.
4. The regression in step 3 showed that B for maladaptive coping as a predictor of distress when RLOC scores were controlled for was .145 which was not significant (p=.245). Partial mediation has occurred. The amount of mediation was .426-.145=.281.

There is evidence that RLOC mediated the relationship between maladaptive coping and distress, whereby an increase in maladaptive coping was associated with a decrease in internality of locus of control, which in increases decreased distress. This is shown in Figure 4.3.

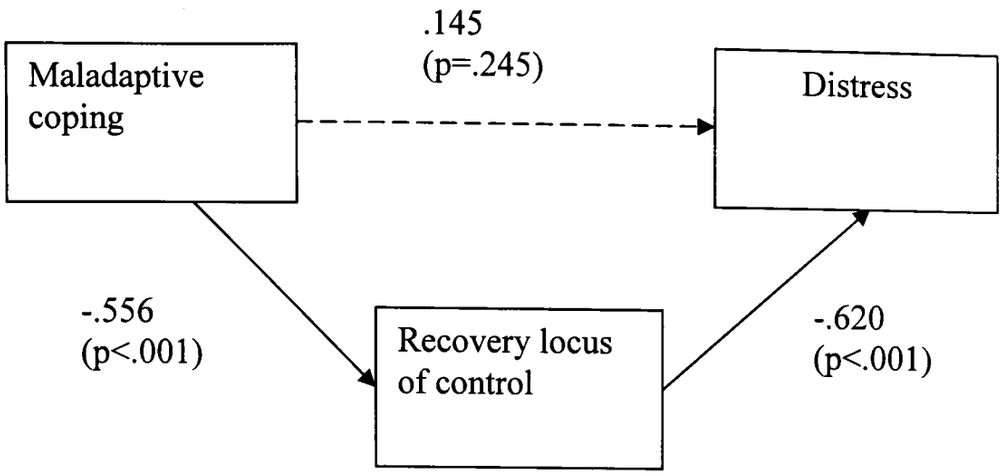


Figure 4.3 Relationship between maladaptive coping and distress mediated by recovery of locus of control

The z score of the mediated effect was calculated as for adaptive coping and was 1.760. As 1.760<1.96, therefore the mediated effect was not significant (p>.05)

4.3.10 Description of follow-up sample

Ninety two of the original sample were followed up (92%). Of the eight patients who were not reassessed, four declined, two were too ill and two had died. Patients who were followed up were compared to those not followed up on age, gender and baseline Barthel scores. Descriptive statistics are shown in Table 4.18. Patients not followed up were non significantly older than those who were followed up (t_{98}=.126, p=.213). An equal number of males and females were not followed up, therefore there was no significant difference (χ^2=.003, p=.953). Patients who were followed up were more independent at baseline as measured on the Barthel Index, but this was not significant (t_{98}=.636, p=.117). The follow up sample did not differ significantly from the sample at baseline in age, gender and Barthel Index scores at baseline. All patients were reassessed at six months post-stroke $\pm$ two weeks. All patients had been discharged from hospital by the follow up assessment.

Table 4.18. Comparisons between patients who were followed up with those who were not followed up on demographic characteristics

	Patients followed up (n=92)	**Patients not followed up (n=8)**	**Comparison p value**
Age			
Mean	69.80	74.13	.213
SD	9.19	11.28	
Gender			
Male (N)	47	4	.953
Female (N)	45	4	
Barthel Index			
Mean	11.84	9.13	.117
SD	4.61	5.22	

SD=Standard deviation

Fifty five (60%) of the ninety two patients lived with their spouse at follow up, 28 (30%) lived alone, three (3%) lived with their son/daughter and six (7%) were living in a residential/nursing home. Fourteen (15%) of the patients had originally suffered at TACS, 41 (45%) PACS, 11 (12%) POCS and 21 (23%) LACS, and for the remaining patients stroke classification was known.

Independent samples t-tests were performed to see whether scores on the measures of emotional distress at baseline were significantly different for patients who were followed up at six months compared with those who were not followed up. The results are summarised in Table 4.19.

Table 4.19. Comparisons between patients follow up and those who were not followed up on distress scores

	Patients followed up	Patients not followed up	Comparison p value
VAMS-HE			
Mean	157.91	149.13	.844
SD	115.65	175.58	
VASES-D			
Mean	42.66	43.25	.833
SD	7.28	7.28	
SADQ-H			
Mean	12.28	12.75	.883
SD	8.35	10.42	
HADS distress			
Mean	8.08	10.60	.312
SD	5.25	6.99	
BDI-II			
Mean	9.34	14.00	.117
SD	6.48	11.47	

None of the distress scores at baseline were significantly different between patients who were followed up and those who were not reassessed at follow up. However due to the small number of people not followed up (n=8) it is difficult to make strong conclusions. This indicates that the follow up sample was representative of the baseline sample in terms of level of emotional distress.

4.3.11 Measures of emotional distress at follow up

Ninety two patients were reassessed on the VASES and VAMS at six months. Seventy three patients completed the HADS and the BDI-II. The remaining 19 patients did not complete the HADS and the BDI-II as they were classified as aphasic on the Sheffield Screening Test. The SADQ-H was completed by a spouse, carer or relative for 88 of the patients. The remaining four questionnaires were not

returned to the researcher. Descriptive statistics for the measures of distress are shown in Table 4.20. Paired sample t-tests were used to compare baseline and follow up scores

Table 4.20. Descriptive statistics for measures of emotional distress at follow up

Measure (n)	Range of possible scores	Range	Follow up		Baseline		Comparison p
			Mean	SD	Mean	SD	
VASES-D (92)	11-55	22-55	43.71	7.56	42.77	7.23	.063
VAMS-HE (92)	0-600	0-510	176.68	116.57	157.21	120.33	.028*
SADQ-H (88)	0-63	0-41	12.11	7.92	12.33	8.49	.664
HADS-D (73)	0-21	0-11	4.30	3.15	3.90	3.00	.166
HADS-A (73)	0-21	0-9	4.30	2.45	4.37	3.11	.148
HADS-total (73)	0-42	0-19	8.66	5.23	8.27	5.33	.408
BDI-II (73)	0-63	0-28	8.68	6.15	9.70	6.98	.377

SD=standard deviation

*$p \leq .05$

VAMS-HE were significantly higher at follow up compared with baseline, indicating greater distress at six months. All other scores were not significantly different. Mean scores on the HADS total score, HADS subscale scores and the BDI-II remained low at follow up.

Comparison of aphasic and non aphasic patients at follow up

Nineteen (21%) of the 92 patients reassessed at follow up were classified as 'aphasic' on the Sheffield Screening Test. Table 4.21 shows descriptive statistics for aphasic and non aphasic patients on the VASES-D, VAMS-HE and SADQ. Scores for aphasic and non aphasic patients were compared using Independent Samples t-tests.

Table 4.21. Comparison of aphasic and non aphasic patients at follow up on distress scores

Scale	Aphasic (n=19)		Non aphasic (n=73)		Comparison p
	Mean	SD	Mean	SD	
VASES-D	39.11	8.86	44.90	6.75	.002
VAMS-HE	274.32	140.26	151.27	95.31	.002
SADQ-H[1]	14.39	9.27	11.52	7.49	.173

[1]SADQ was returned for 18 of the 19 aphasic patients
SD standard deviation
** p<.01

Aphasic patients scored significantly lower than non aphasic patients on the VASES-D and significantly higher on the VAMS-HE, indicating that the aphasic patients were more distressed. There was no significant difference for the SADQ-H scores between aphasic and non aphasic patients. These findings replicate the baseline results.

Classification of depression and distress at follow up

SADQ-H

SADQ-H questionnaires were returned for 87 patients at six months follow up. Using the cut-off of 17/18, 24 of the 87 patients (28%) were classified as depressed. This is slightly lower than the 33% prevalence at baseline. McNemar Chi-Square Test was performed to see whether there were changes in depression classification between

baseline and follow up. That is, were the same patients classified as depressed at baseline and follow up. No significant difference was found between patients' classification of depression at baseline and at follow up (p=.424).

HADS

Using a cut-ff score of 7/8 on the depression subscale of the HADS, 19 (26%) of the 73 patients who completed the HADS at follow up were classified as depressed. This is slightly higher than the 21% found at baseline. McNemar test showed that there was no significant difference between patients' classification of depression at baseline and follow up (p=.332).

Using a cut-off of 7/8 on the anxiety subscale of the HADS, 11 (15%) of the 73 patients who completed the HADS at follow up were classified as anxious. This is lower than the 22% at baseline. McNemar test showed there was no significant difference in patients' anxiety classification at baseline and at follow up (p=.302).

A cut-off of 10/11 was used on the HADS total score to screen for depression. Thirty one (40%) of the 78 patients were classified as depressed. McNemar test showed that there was no significant different in patients' classification of depression using the HADS total score at baseline and at follow up (p=.90).

BDI-II

Using a cut-off of 13/14 on the BDI-II, 13 (18%) of the 73 patients scored as depressed at follow up. This is lower than the prevalence rate of 25% found at baseline. McNemar test showed there was no significant difference in patients' classification of depression using BDI scores at baseline and at follow up (p=.454).

4.3.12 Description of assessment scores at follow up

Table 4.22 shows descriptive statistics of assessment scores at follow up. Paired samples t-tests were used to compared baseline and follow up results on each of the assessments.

Table 4.22. Descriptive statistics of assessment scores at follow up

Measure	n	Range of possible scores	Range	Follow up		Baseline		Comparison p
				Mean	SD	Mean	SD	
Sheffield Screening Test total*	92	0-20	4-20	17.72	3.29	17.11	3.58	.001
Receptive subscale*	92	0-9	2-9	7.90	1.34	7.55	1.49	<.001
Expressive subscale*	92	0-11	1-11	9.80	2.32	9.56	2.58	.001
Barthel Index*	92	0-20	3-20	18.39	3.51	11.62	4.69	<.001
EADL total*	92	0-66	5-66	43.63	13.38	n/a (not completed at baseline)		
EADL mobility*	92	0-18	0-18	12.37	4.65			
EADL kitchen*	92	0-15	2-15	12.47	3.60			
EADL domestic*	92	0-15	0-15	9.48	4.65			
EADL leisure*	92	0-18	1-18	9.30	3.56			

				Follow up		Baseline		Comparison p
SCQR total	73	0-63	0-54	16.05	11.10	14.81	10.09	.488
SCQR positive cognitions total	73	0-27	0-28	5.75	5.12	5.18	4.72	.760
SCQR negative cognitions total	73	0-36	0-40	11.02	6.90	9.63	6.90	.410
RLOC*	73	9-45	27-45	37.23	3.63	35.53	4.71	<.001
COPE adaptive coping*	73	14-56	27-50	42.04	5.11	41.29	6.05	.006
COPE maladaptive coping	73	10-40	11-30	16.60	4.52	17.72	5.50	<.001
SOS*						n/a		
Actual Emotional	73	0-7	1-7	5.03	1.57	Not completed at baseline		
Ideal Emotional	73	0-7	4-7	6.04	0.86			
Emotional Discrepancy	73	0-7	0-5	1.01	1.28			
Actual Practical	73	0-7	1-7	5.03	1.52			
Ideal Practical	73	0-7	3-7	6.05	.80			
Practical Discrepancy	73	0-7	0-5	1.03	.12			

EADL Extended Activities of Daily Living Scale; SCQR Stroke Cognitions Questionnaire Revised; RLOC Recovery Locus of Control Scale; SOS Significant Others Scale; * Higher score is positive

Sheffield Screening Test total scores and expressive and receptive subscale scores were all significantly higher at follow up compared with baseline scores. Therefore communication impairment was significantly reduced at follow up.

There was a ceiling effect for the Barthel Index as the mean score approached the maximum of 20 (indicating independence) and the standard deviation was small. The decrease in Barthel scores between baseline and follow up was significant.

There was a significant increase in RLOC scores between baseline and follow up which means that locus of control became more internal. The use of adaptive coping strategies significantly increased between baseline and follow up and there was a corresponding significant decrease in of maladaptive coping strategies between baseline and follow up.

4.3.13 Associations with measures of emotional distress at follow up – whole sample

Prior to carrying out multiple linear regression to identify follow-up predictors of emotional distress at follow up, preliminary analyses were conducted to identify which variables that were assessed at follow up were related to emotional distress at follow up. Analyses were firstly carried out on the whole sample, and additional analyses were carried out on the non aphasic patients.

The same measures of emotional distress were used at follow up (VASES-D and SADQ-H) This allows comparison to baseline. VASES-D scores were available for all 92 patients who were reassessed and SADQ-H scores were available for 87 patients (the remaining five questionnaires were not returned to the researcher).

One-way ANOVAs were performed to calculate whether VASES-D and SADQ-H scores were significantly different for categorical variables with more than two groups. Independent sample t-tests were performed for categorical variables with two groups. Levene's test for homogeneity of variance was not violated for any of the comparisons. Pearson's correlations were performed for continuous variables. Comparisons for categorical variables are shown in Table 4.23.

Table 4.23. Comparisons between VASES-D and SADQ-H scores for categorical variables

Characteristic	VASES-D				SADQ-H			
	n	Mean	SD	p	n	Mean	SD	p
Gender								
Male	47	42.74	8.44	.214	44	12.68	8.35	.502
Female	45	44.74	6.47		43	11.53	7.49	
Marital status								
Single	5	42.40	12.20	.645	3	10.33	4.93	.291
Married	54	43.17	7.78		51	11.18	7.50	
Divorced	3	48.00	7.21		3	8.33	1.53	
Widowed	30	44.47	6.42		30	14.27	8.88	
Living arrangements								
Alone	28	46.46	6.69	.045	26	12.77	7.40	.328
With spouse	55	43.02	7.61		52	11.27	7.29	
With son/daughter	3	42.33	4.93		3	10.67	9.07	
Nursing/residential home	6	37.83	8.98		6	17.33	13.60	

p Probability

SD standard deviation

VASES-D and SADQ-H scores at follow up did not significantly differ between men and women. This replicates the finding at baseline. There was no significant difference in VASES-D and SADQ-H scores at follow up for patients according to marital status. Three patients were divorced and five were single. Categories were combined to compare VASES-D scores for those who were married (mean 43.17, SD=7.78) with those who were divorced, widowed or single (mean 44.47, SD=7.27), but no significant difference was found (t_{90}=.815, p=417). Similarly, SADQ scores did not significantly differ between patients who were married (mean 11.18, SD=7.50) compared to those who were divorced, widowed or single (mean 13.44, SD=8.40) (t_{85}=1.322, p=.190). This also replicates the finding at baseline.

VASES-D scores were lower for patients living in a nursing home at follow up compared with those who living alone, with their spouse, or with their son/daughter. The overall difference was significant ($F_{3,88}$=2.788, p=.045). Tukey's post hoc test showed the difference between VASES-D scores was significant for those living in a nursing home compared with those who lived alone (p=.05) but no other comparisons were significant (p>.05). Therefore, patients living in a nursing home were more distressed than those living alone. Six patients were living in a nursing home. It is likely that those patients living in a nursing home were more disabled in personal ADL than the other patients. A one-way ANOVA was conducted to test this. Barthel scores were lowest for patients living in a nursing home (mean 8.33 SD=4.27) compared with those living alone (mean 19.54, SD=.74), living with a spouse (mean 19.04, SD=2.18) and living with a son/daughter (mean 16.00, SD=6.08). This overall difference was significant ($F_{3,88}$=45.97, p<.001). Tukey's post hoc test showed that the difference was significant between patients living in a nursing home and all other patients (living along, with spouse or with son/daughter)

(all p<.001). SADQ-H scores were not significantly different for living arrangements at follow up.

Table 4.24 shows the correlations between continuous variables at follow up and the VASES-D and SADQ-H scores at follow up.

Table 4.24. Correlations with VASES-D and SADQ-H scores at follow up

	VASES-D		SADQ-H	
	r	p	r	p
Age	.047	.659	.044	.683
Sheffield Screening Test total	.507	<.001***	-.216	.044*
Sheffield Screening Test receptive	.335	.001**	-.223	.038*
Sheffield Screening Test expressive	.490	<.001***	-.181	.093
Barthel Index	.364	.001***	-.238	.026*
EADL total	.377	.001***	-.235	.029*
EADL mobility	.358	.001***	-.231	.031*
EADL kitchen	.290	.005**	-.111	.304
EADL domestic	.295	.004**	-.144	.182
EADL leisure	.272	.009**	-.275	.010**

r Pearson's correlation
p Probability
*** p≤.001 ** p≤.01 * p≤.05

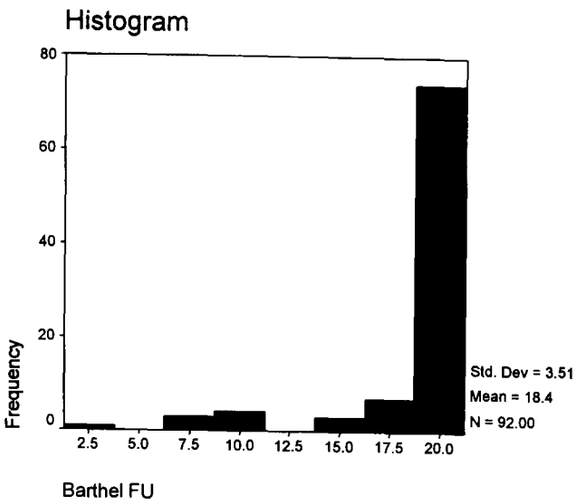
Age was not significantly correlated with distress scores on the SADQ-H or the VASES-D; this replicates the finding at baseline. Patients who scored higher on the Sheffield Screening Test total and subscales had significantly higher scores on the VASES-D, indicating that less distress. Sheffield Screening Test total scores and

receptive subscale scores were significantly negatively correlated with SADQ-H scores. Sheffield Screening Test expressive scores were not significantly correlated with SADQ-H scores. This differs to baseline where Sheffield Screening Test total and subscale scores were unrelated to observer rated mood on the SADQ-H.

There was a significant positive correlation between Barthel Index and VASES-D scores at follow up, meaning that patients who were more independent in personal ADL were less distressed. SADQ-H scores were significantly negatively correlated with scores on the Barthel Index, indicating that greater independence in personal ADL was also associated with observer ratings of mood. This was also found at baseline. EADL total scores and subscale scores at follow up were significantly positively correlated with VASES-D scores. Patients who were more independent in extended ADL were less distressed. With regard to SADQ-H scores at follow up, EADL total scores and scores on the mobility and leisure subscales of the EADL were significantly negatively correlated with SADQ-H scores. Scores on the kitchen and domestic subscale scores were unrelated to SADQ-H scores at follow up.

Scores on the Barthel Index were highly correlated with the EADL total score ($r=.867$, $p<.001$), mobility ($r=.840$, $p<.001$), domestic ($r=.684$, $p<.001$) and leisure (.407, $p<.001$) subscales. These correlations are greater than the recommended threshold of .80, indicating multicollinearity. Inclusion of both the Barthel Index and EADL scores into a regression analysis may not be informative due to the high level of shared variance. Also, the Barthel Index at follow up had a ceiling effect and the distribution was negatively skewed as shown in Figure 4.4; 55 of the 92 patients (60%) scored the maximum of 20.

Fig 4.4. Distribution of scores on the Barthel Index at follow up



When multicollinearity occurs it is recommended that the researcher considers collecting further data, or removing or combining variables. It was not appropriate to collect more data as the Barthel Index is known to have a ceiling effect at this time post-stroke (Wade, 1992). Another approach was to dichotomise Barthel Index scores. Gladman et al (1993) dichotomised scores, such that 0-16 corresponded to 'dependent' and 17-20 was 'independent'. This method was followed in the present study as it allowed Barthel scores to be used and overcame the problem of the severe skew. Eleven patients (12%) were classified as dependent and 81 (88%) independent. Independent Samples t-tests were performed using VASES-D and SADQ-H follow up scores as dependent variables. The results are shown in Table 4.25.

Table 4.25. Comparison of VASES-D and SADQ follow up scores for dependent and independent patients

	Dependent (BI≤16)		**Independent (BI≥17)**		**Comparison p value**
	Mean	**SD**	**Mean**	**SD**	
VASES-D	37.82	7.15	44.51	7.30	.005**
SADQ-H	15.45	11.77	11.63	7.12	.316

SD standard deviation; p probability **p<.01

VASES-D scores were significantly higher in patients who were independent on the Barthel Index at follow up compared with those who were dependent (t_{90}=-2.859, p=.005). Mean SADQ-H scores were higher for dependent patients but this difference was not significant (t_{85}=1.508, p=.316).

4.3.14 Factors predicting emotional distress at follow up – all patients

Regression model for VASES-D at follow up

Multiple linear regression was carried out to evaluate a model for the prediction of emotional distress on the VASES-D at six months using assessment scores collected at the follow up assessment. The variables found to be significantly associated with greater emotional distress at six months were living in a nursing home, greater communication impairment on the Sheffield Screening Test (total, receptive and expressive scores), dependence on the Barthel Index, and lower independence in extended activities of daily living.

Living arrangements were not entered into the regression as only six patients were living in a nursing home at follow up. Also, it is likely that living in a nursing home was due to being more disabled. This was demonstrated by the fact that Barthel Index scores were significantly lower for those patients living in a nursing home compared with those living alone, with a spouse or with a son/daughter. Therefore, to avoid collinearity, the dichotomised Barthel Index scores at follow up were entered into the regression. Sheffield Screening Test receptive and expressive scores were entered into the regression as they were significantly associated with distress and this allowed comparison to baseline. EADL total scores were also entered as a predictor variable as they were also associated with distress. Although the four subscale scores

were also associated with distress, due to the sample size it was not desirable to have a large number of predictor variables, and the subscale scores were correlated with one another.

Forward regression was conducted in the same way as at baseline. The results of the regression are summarised in Table 4.26.

Table 4.26. Regression model for follow up VASES-D scores using follow up variables

	B (95% CI)	SE	Standardised B	t	Significance of t	Partial correlation
Sheffield Expressive	1.381 (.796-1.967)	.295	.424	4.685	<.001***	.445
EADL total	.156 (0.540-.258)	.051	.276	3.051	.003**	.308
Sheffield Receptive	.008			.074	.941	.008
Barthel Index	.062			.348	.729	.037

CI confidence interval SE standard error
**p≤.01 ***p≤.001

Sheffield Screening Test expressive scores and EADL total scores were significant predictors of VASES-D scores at follow up. Lower impairment in expressive communication and greater independence in extended activities of daily living were significant predictors of lower emotional distress. Sheffield Screening Test receptive scores and independence on the Barthel Index were not significant predictors and so were removed from the model. The model containing the Sheffield expressive scores and total EADL scores was significant ($F_{2,89}$=20.183, p<.001). The R^2 for the model

was .312, which means it accounted for almost one third of the variance in VASES-D scores at follow up. This was slightly greater than the R^2 of .236 found at baseline.

VASES-D scores at follow up were significantly higher (indicating less emotional distress) for patients classified as independent on the Barthel Index at follow up compared with those who were dependent. This was not significant in the regression. The relationship between independence on the Barthel Index and emotional distress may be mediated by extended activities of daily living, as Barthel Index and EADL scores were highly correlated. The prediction is that independence on the Barthel Index had a positive influence on EADL (i.e. greater independence), which subsequently had a positive influence on VASES-D scores (lower distress).

This was tested using the steps recommended by Baron and Kenny (1986). The dichotomised Barthel Index classification was used in the analysis.

1. Linear regression using VASES-D scores as the dependent variable and Barthel Index as the predictor variable showed that the B coefficient was 6.688 (standardised β=.289) which was significant ($p<.005$). Condition 1 was met.
2. Show that the Barthel Index is a significant predictor of EADL using regression. This showed that the B coefficient was 31.692 (standardised β=.773) and was significant ($p<.001$). Condition 2 was met.
3. Multiple linear regression was conducted using the Barthel Index and EADL as predictor variables and the VASES-D as the dependent variable. The B coefficient for the EADL was .213 (standardised β=.377) which was significant ($p<.001$). Condition 3 was met.

4. The multiple linear regression carried out in step three showed that the B coefficient for the Barthel Index when EADL scores were controlled for was .007 which was not significant (p=.962). There is almost full mediation as the B value close to 0. The amount of mediation was 6.688-.007=6.681.

There was therefore evidence that the EADL mediated the relationship between the Barthel Index and distress, whereby independence in personal ADL was associated with an increase in independence in extended activities of daily living, which in turn decreased distress. The results of the mediation analysis are summarised in Figure 4.5

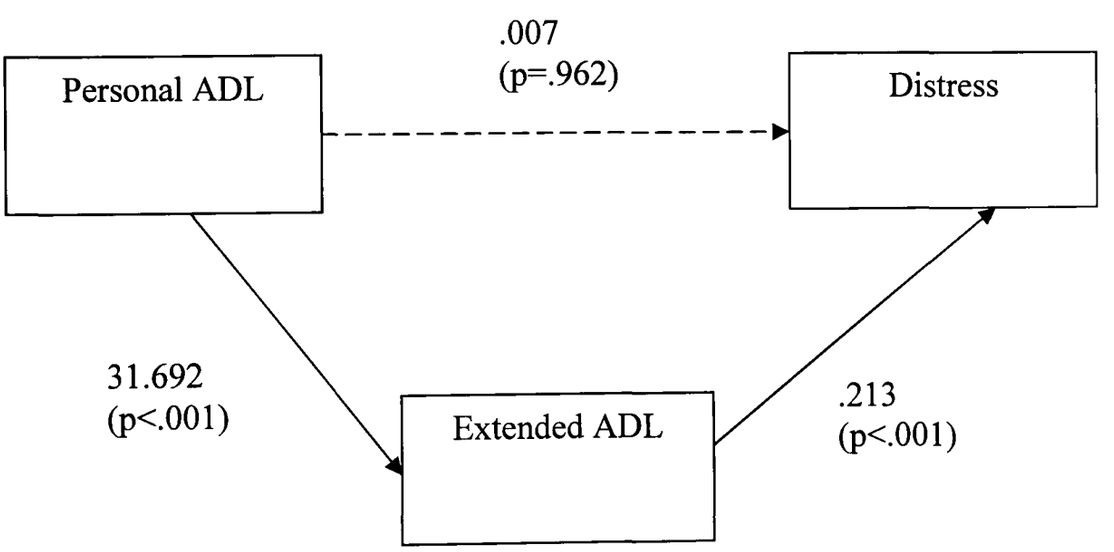


Figure 4.5. The relationship between basic ADL and distress, mediated by extended ADL

The significance of the mediated effect was calculated in the same manner as at baseline. The z score of the mediated effect was 3.681. As 3.681>1.96 the mediated effect was significant at p<.05.

Regression model for SADQ-H at follow up

Multiple linear regression was carried out to evaluate at model for the prediction of follow up SADQ-H scores using assessment information collected at follow up. The receptive subscale and total score of the Sheffield Screening Test were significantly associated with distress. The total score will be entered into the regression to see whether overall impairment in communication is a predictor of SADQ-H scores. EADL total scores and mobility and leisure subscale scores were associated with SADQ-H scores. The total EADL score was entered into the regression. Forward regression was performed. The results of the regression are shown in Table 4.27.

Table 4.27. Regression model for follow up SADQ-H scores using follow up variables

	B (95% CI)	SE	Standardised B	t	Significance of t	Partial correlation
EADL total	-.139 (-.263- -.015)	.062	-.235	-2.228	.029*	-.235
Sheffield Screening Test total	-.169			-1.563	.122	-.168

CI confidence interval SE standard error
p≤.05

EADL total scores were a significant predictor of SADQ-H scores at follow up such that an increase in independence in EADL was predictive of a decrease in distress. The Sheffield Screening Test total score was not significant. The regression model was significant ($F_{1,85}$=4.964, p=.029). The R^2 for the model was .055 which means the EADL accounted for 5% of the variance in SADQ-H scores at follow up. This is

comparable to the R^2 for the model at baseline in which Barthel Index scores were a significant predictor.

4.3.15 Associations between baseline assessments and emotional distress at follow up – whole sample

In order to develop a regression model to predict emotional distress scores at six months using baseline assessments and information on stroke characteristics collected at baseline, associations between these assessments needed to be explored. In the analysis of follow up predictors of emotional distress at follow up age, gender and marital status were found not to be significantly associated with follow up distress scores. Independent t tests were used for categorical variables with two categories and one-way ANOVAs were used for categorical variables with more than one category. These are summarised in Table 4.28.

Table 4.28. Comparison between VASES-D and SADQ-H scores for baseline categorical variables

Baseline characteristic	VASES-D				SADQ-H			
	n	Mean	SD	p	n	Mean	SD	p
Living arrangements								
Living alone	34	44.74	7.49	.596	32	14.28	8.52	.083
Living with spouse	54	43.17	7.78		51	11.18	7.50	
Living with son/daughter	4	42.25	5.19		4	6.75	2.06	
History of depression					n/a (SADQ-H was only returned for one patient who had a history of depression)			
Yes	2	33.50	4.95	.053				
No	90	43.93	7.47					
Previous stroke								
Yes	43.30	10	5.81	.858	9	11.00	6.02	.658
No	43.76	82	7.78		78	12.24	8.13	
Side of lesion								
Left	39	43.36	7.95	.892	36	13.11	8.30	.602
Right	46	43.59	7.45		45	11.31	7.47	
Bamford classification								
TACS	14	37.36	8.88	.006	13	16.15	10.79	.254
PACS	41	45.22	7.22		39	11.69	7.05	
POCS	11	43.36	5.33		11	11.73	6.62	
LACS	21	45.04	6.70		19	10.68	8.01	

p Probability, SD=standard deviation

Two of the four patients who had a history of depression documented in their medical notes at baseline were reassessed at follow up. VASES-D scores at follow up were lower for those patients who had a pre-stroke history of depression but this difference was not significant. VASES-D scores were non significantly lower at

follow up for patients with a pre-stroke history of depression, but only two patients were in this category. SADQ-H scores were only available for one patient with a history of depression was reassessed at follow up, therefore analyses were not performed. There was no significant difference for VASES-D and SADQ-H scores at follow up for patients who had suffered a previous stroke compared with those who had not suffered a previous stroke. These findings replicate baseline.

VASES-D and SADQ-H scores at follow up were not significantly different for patients who had a right sided lesion compared with those who had a left sided lesion and this was also found at baseline. VASES-D scores were lower for patients who were classified as TACS compared with PACS, POCS and LACS. The overall difference was significant. Tukey's post hoc test showed that the difference was significant between TACS and PACS (p=.004), TACS and POCS (p=.045) and TACS and LACS (p=.014). TACS patients were more distressed on the VASES-D than other stroke classifications. Similar trends were found at baseline but were not significant at that point. There was a trend for SADQ-H scores to be lower in TACS patients, this difference was not significant. This replicates the findings at baseline.

Pearson's correlations were calculated between baseline assessments using the Barthel Index, Sheffield Screening Test, VASES-D and SADQ scores, and follow up scores on the VASES-D and SADQ-H. These are shown in Table 4.29.

Table 4.29. Correlations between baseline assessments and scores on the VASES-D and SADQ-H at six months.

	VASES-D		SADQ-H	
	r	p	r	p
Barthel Index (baseline)	.459	<.001***	-.225	.036*
Sheffield Screening Test total at baseline	.418	<.001***	-.191	.076
Sheffield Screening Test receptive (baseline)	.288	.005**	-.169	.117
Sheffield Screening Test expressive (baseline)	.352	.001***	-.167	.122
VASES-D (baseline)	.616	<.001***	-.051	.640
SADQ (baseline)	-.389	<.001***	.338	.003**

r Pearson's correlation

p probability

*p≤.05 **p≤.01 ***p≤.001

Lower independence in basic ADL, greater communication impairment and distress at baseline were significantly associated with emotional distress measured on the VASES-D at six months. Lower observer-rated mood (SADQ-H) at baseline was also associated with lower VASES-D scores at follow up.

Lower independence in self-care ADL and lower observed mood (SADQ-H) at baseline were associated with lower mood measured on the SADQ-H at six months. Scores on the Sheffield Screening Test at baseline were not significantly correlated with follow up scores on the SADQ-H.

4.3.16 Baseline factors predicting follow up distress – whole sample

Regression model for VASES-D follow up scores using baseline assessments

Multiple linear regression was conducted to evaluate a model for the prediction of emotional distress at six months using baseline assessments. Patients who suffered a TACS had lower mood than those who suffered a PACS, POCS or LACS. The Bamford classification variable was recoded such that 1=TACS stroke and 0=not TACS. This also reduces the number of variables entered into the regression. Sheffield Screening Test receptive and expressive subscale scores were entered into the regression as they were both significantly associated with distress. Age, gender, pre-stroke history of depression, previous stroke, side of lesion and living arrangements recorded at baseline were not significantly associated with VASES-D scores at follow up and were not entered into the regression. Forward regression was performed. The results of the regression are summarised in Table 4.30.

Table 4.30. Regression model for predicting follow up VASES-D scores using baseline assessments

	B (95% CI)	SE	Standardised B	t	Significance of t	Partial correlation
Sheffield Expressive	1.151 (.632-1.671)	.261	.411	4.407	<.001***	.433
Barthel	.497 (.196-.797)	.151	.307	3.287	.001***	.338
Sheffield Receptive	.017			.159	.874	.017
TACS	.154			1.751	.084	.189

CI confidence interval
SE standard error
*** p≤.001

Less impairment in expressive communication and greater independence in personal at baseline were significant predictors of lower emotional distress on the VASES-D at six months. Receptive communication impairment and suffering a TACS stroke were not significant in the regression model. The model containing the expressive subscale and the Barthel Index was significant ($F_{2,84}$=22.146, p<.001). The R^2 for the model was .345 and so it accounted for 34.5% of the variance in VASES-D scores at six months. This was slightly higher than the 23.6% found with the baseline model.

VASES-D scores at baseline were significantly correlated with VASES-D scores at follow up (r=.616, p<.001). It would be informative to include VASES-D scores in the regression analysis to see whether emotional distress at baseline predicts emotional distress at six months. This approach has been used in a study of depression after stroke which conducted multiple linear regression (Berg et al, 2003). The regression was repeated including baseline VASES-D scores. VASES-D scores at baseline were entered into the regression in the first step. Sheffield expressive and receptive scores, Barthel Index and TACS were entered in the second step. However, The results of this regression are shown in Table 4.31.

Table 4.31. Regression model for predicting follow up VASES-D scores using baseline assessments, including baseline VASES-D scores

	B (95% CI)	SE	Standard-ised B	t	Significance of t	Partial correlation
VASES-D	.491 (.310-.672)	.091	.493	5.406	<.001***	.517
Sheffield expressive	.728 (.206-1.249)	.262	.267	2.777	.007**	.297
TACS	3.169 (.348-5.990)	1.41	.173	2.236	.028*	.243
Barthel	.221			1.653	.102	.182
Sheffield receptive	-.205			-.478	.634	-.053

CI confidence interval

*p≤.05, ** p≤.01, ***p≤.001

SE standard error

VASES-D scores at baseline were a significant predictor of emotional distress on VASES-D at six months, such that patients with less distress at baseline had lower distress at six months. Scores on the expressive subscale at baseline remained a significant predictor of VASES-D scores at six months. Suffering a TACS rather than a PACS, POCS or LACS was now a significant emotional distress at six months, while independence in personal ADL was no longer significant in the regression. Scores on the receptive subscale of the Sheffield Screening Test remained non significant in the regression model. The model containing the significant predictors was significant ($F_{5,80}$=19.405, p<.001). The R^2 for the model containing only the VASES-D baseline scores was .428. The R^2 for the final model containing

the significant predictors was .548 which means it accounted for just over half of the variance in VASES-D scores at six months.

Regression model for SADQ-H follow up scores using baseline assessments

Regression analysis was performed to evaluate a model for the prediction of SADQ scores at six months follow up using baseline assessment scores. Barthel Index scores at baseline were both significantly associated with SADQ-H follow up scores and were entered as predictor variables into the regression equation. No other baseline variables were significantly associated with SADQ-H follow up scores. Forward linear regression was performed. Results are summarised in Table 4.32.

Table 4.32. Regression model for predicting follow up SADQ scores using baseline assessments

	B (95% CI)	SE	Standardised B	t	Significance of t	Partial correlation
Barthel Index	-.392 (-.759- -.026)	.184	-.225	-2.127	.036*	-.225

CI confidence interval
SE standard error
*p≤.05

Greater independence in personal ADL assessed at baseline was a significant predictor of lower SADQ-H scores (less emotional distress) at six months. This model was significant ($F_{1,85}$=4.523, p=.036). The R^2 for the model was .051 which means the model accounted for about 5% of the variance in SADQ-H scores at six months. This is comparable to the baseline regression model that included the Barthel Index.

SADQ-H scores at baseline were significantly correlated with SADQ-H scores at follow up (r=.338, p=.003). The regression analyses for predicting follow up SADQ-H scores was repeated including baseline SADQ-H scores. Baseline SADQ-H scores were entered in the first step and Barthel Index scores in the second step. The results are shown in Table 4.33.

Table 4.33. Regression model for predicting follow up SADQ-H scores using baseline assessments including baseline SADQ scores

	B (95% CI)	**SE**	**Standard-ised B**	**t**	**Significance of t**	**Partial correlation**
SADQ-H (baseline)	.288 (.078-.497)	.105	.303	2.739	.008**	.303
Barthel Index	-.265			-1.404	.164	-.161

CI confidence interval

SE standard error

**p≤.01

SADQ-H scores at baseline were significant predictors of SADQ-H scores at follow. Barthel Index scores were no longer significant. The model containing baseline SADQ-H scores was significant ($F_{2,74}$=5.874, p=.004). The R^2 for the model was .137 and so it accounted for 14% of the variance in SADQ-H scores at six months. Including baseline SADQ-H scores in the regression accounted for an additional 9% of the variance in SADQ-H scores at follow up compared with the baseline model.

4.3.17 Associations with emotional distress at follow up - non aphasic patients

Associations with HADS distress scores at follow up – non aphasic patients

In order to develop a regression model of emotional distress measured using the HADS total score at follow up, associations between follow up assessments and HADS total scores at follow up were explored. Independent samples t tests were used to compared distress scores for categorical variables and one-way ANOVAs were used for categorical variables with more than two groups. These are summarised in Table 4.34. Seventy three patients at follow up completed the HADS.

Table 4.34. Comparisons between HADS distress scores for baseline demographic variables

Characteristic	HADS distress		
	Mean	SD	p
Gender			
Male	8.76	5.11	.871
Female	8.56	5.41	
Marital status			
Single	7.50	2.89	.148
Married	7.93	5.11	
Divorced	5.00	5.66	
Widowed	10.68	5.40	
Living arrangements			
Alone	8.87	5.31	.165
With spouse	8.04	4.99	
With son/daughter	17.00	n/a (n=1)	
Nursing/residential home	12.25	6.08	

p Probability

SD standard deviation

HADS distress scores at six months were not significantly different between men and women. Distress scores were highest at follow up for those who were widowed although this difference was not significant ($t_{3,69}$=1.843, p=148). This was the same as the finding at baseline. Distress scores did not significantly differ according to living arrangement at baseline. When the one patient who lived with their son/daughter at baseline was removed from the analysis there was still no significant difference in HADS distress scores at follow up ($F_{2,69}$=1.295, p=.280). This was the same as at baseline.

Pearson's correlations were calculated between HADS distress scores at follow up and follow up scores on the Barthel Index, EADL, Sheffield Screening Test, Recovery Locus of Control Scale, Brief COPE (adaptive and maladaptive coping), Recovery Locus of Control (RLOC) and Significant Others Scale (SOS). The results are shown in Table 4.35.

Table 4.35. Correlations between follow up assessments and HADS distress scores at follow up

	HADS total	
	r	P
Age	.144	.224
Sheffield Screening Test total	-.156	.187
Sheffield Screening Test receptive	-.144	.225
Sheffield Screening Test expressive	-.077	.518
Barthel Index	-.456	<.001***
EADL total	-.604	<.001***
EADL mobility	-.613	<.001***
EADL kitchen	-.380	.001***
EADL domestic	-.485	<.001***
EADL leisure	-.455	<.001***
RLOC	-.475	<.001***
Adaptive Coping	-.331	.004**
Maladaptive Coping	.410	<.001***
Significant Others Scale		
Actual Emotional	-.521	<.001***
Ideal Emotional	-.105	.375
Emotional Discrepancy	.572	<.001***
Actual Practical	-.543	<.001***
Ideal Practical	-.212	.072
Practical Discrepancy	.531	<.001***

r Pearson's correlation

p probability level

*** p≤.001, ** p≤.01, *p≤.05

Age was not associated with distress scores at follow up. Communication impairment on the Sheffield Screening Test total and subscale scores were not

significantly correlated with distress. Barthel Index scores at follow up remained correlated with distress scores, with patients more independent in personal ADL reporting less distress. It was noted in the analysis of the overall group of patients that the Barthel Index was severely negatively skewed at follow up. The Barthel Index was again dichotomised such that 0-16=dependent and 17-20=independent. Using this cut-off, the HADS distress scores for dependent patients (mean 14.50, SD=4.75) were higher than independent patients (mean 7.94, SD=4.84), indicating greater emotional distress, and this difference was significant (t_{71}=3.622, p=.001). EADL total and subscale scores were also significantly negatively correlated with distress scores, which means that patients who were more independent in extended ADL reported lower emotional distress. RLOC and adaptive and maladaptive coping scores remained significantly correlated with distress scores at follow up. With regard to social support measured using the Significant Others Scale (SOS), the actual amount of received emotional and practical support was significantly negatively correlated with distress meaning that greater support was associated with lower distress. The ideal amount of emotional and practical support was not significantly correlated with distress. The discrepancy in the amount of emotional and practical support (ideal minus actual) was significantly positively correlated with distress at six months, with a greater discrepancy in support being associated with higher levels of distress.

Similar to the pattern found at baseline, at follow up RLOC scores were positively correlated with adaptive coping scores (r=.417, p<.001), indicating that internality of locus of control was correlated with greater use of adaptive coping strategies. Partial correlations were carried out to control for this relationship. RLOC scores were still

significantly correlated with distress scores when adaptive coping scores were controlled for (r=-.394, p=.001). However, adaptive coping was no longer significantly correlated with distress when RLOC scores were partialled out (r=-.165, p=.165). This was also found at baseline. Also, RLOC scores were significantly negatively correlated with maladaptive coping (r=-.468, p<.001), with internality of locus of control being associated with less frequent use of maladaptive coping strategies. Partial correlations showed that the relationship between RLOC and distress remained significant when maladaptive coping scores were controlled for (r=-.352, p=.002), although the correlation between maladaptive coping and distress was not significant when RLOC scores were partialled out (r=.251, p=.06).

4.3.18 Factors predicting emotional distress at follow up – non aphasic patients

Regression model for HADS distress scores at follow up

Forward linear regression was carried out to test a model predicting HADS distress scores at follow up using variables assessed at follow up. Barthel Index scores (recoded as dependent and independent), EADL total scores and RLOC scores were entered as they were significantly related to distress. Adaptive and maladaptive coping scores were not entered into the regression as the correlations with distress were no longer significant when RLOC scores were partialled out. Regarding the Significant Others Scale, actual emotional, actual practical, emotional discrepancy and practical discrepancy were also entered into the regression as they were significantly correlated with distress. Ideal emotional and practical scores were not included in the regression as they were not correlated with distress scores. The results of the regression are shown in Table 4.36.

Table 4.36. Follow up regression predicting HADS distress scores using follow up variables

	B (95% CI)	SE	Standard-ised B	t	Significance of t	Partial correlation
EADL total	-.175	.032	-.449			
	(-.240- -.111)			-5.426	<.001***	-.547
Actual practical	-1.190	.290	-.346	-4.099	<.001***	-.442
	(-1.77--.611)			-2.939		
RLOC	-.356				<.001***	-.334
	(-.598- -.114)					
Barthel	.126	.121	-.248	1.015	.314	.122
Actual emotional	-.033			-.140	.889	-.017
Emotional discrepancy	.233			1.791	.078	.212
Practical discrepancy	.043			.277	.783	.034

CI confidence interval
SE standard error
*** $p \leq .001$

EADL total scores, actual practical support and RLOC scores were significant predictors of distress in the model. The overall model was significant ($F_{3,69}=31.342$, $p<.001$). The R^2 for the model was .577 and so it accounted for 57.7% of the variance in HADS distress scores at six months post-stroke.

To check that the exclusion of coping scores from the regression analysis was correct, the regression was repeated including these scores. Adaptive ($t=-1.541$, $p=.128$) and maladaptive coping scores ($t=1.658$, $p=.102$) were not significant in the regression model.

As part of the analysis of baseline results it was found that the relationship between both adaptive and maladaptive coping and distress was mediated by RLOC. This analysis was repeated for the follow up data to check whether this pattern was consistent over time. The mediation analysis was conducted using the steps recommended by Baron & Kenny (1986) as was used previously.

1. Linear regression showed adaptive coping to be a significant predictor of distress. The B coefficient was -.338 (standardised β=-.331) which was significant (p=.004). Condition 1 was satisfied.
2. Adaptive coping was found to be a significant predictor of RLOC. B coefficient was .297 (standardised β=.417) and this was significant (p<.001). Condition 2 was satisfied.
3. Multiple linear regression was conducted using adaptive coping and RLOC as predictor variables and distress as the dependent variable. RLOC was found to be a significant predictor of distress. B coefficient was -.588 (standardised β=-.409) and this was significant (p=.001). Condition 3 was met.
4. Multiple regression from step 3 showed that the B coefficient for adaptive coping predicting distress when RLOC was controlled for was -.164 and this was not significant (p=.165). Partial mediation has occurred as although B was no longer significant the value of B was >0. The amount of mediation was -.331 - -.164 = -.167.

The finding that RLOC mediated the relationship between adaptive coping and distress replicated the finding at baseline, in which greater use of adaptive coping

was associated with a more internal locus of control, which in turn was associated with decreased distress. This is illustrated in Figure 4.6.

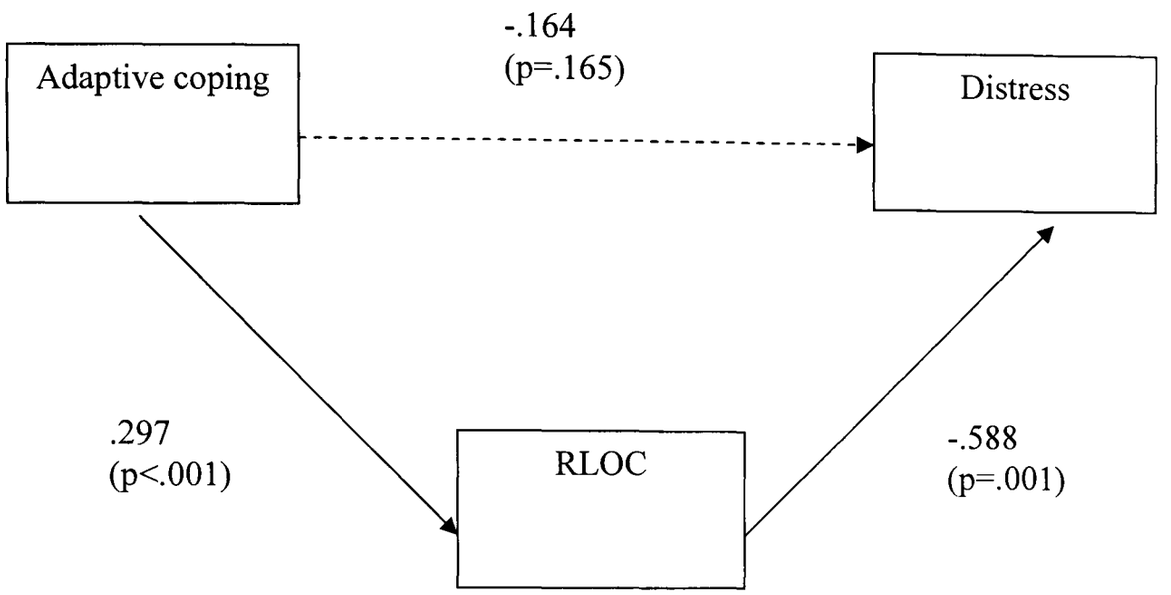


Fig 4.6. Relationship between adaptive coping and distress at follow up, mediated by recovery locus of control.

The significance of the mediated effect was tested using the same procedure as at baseline. The z score of the mediated effect was –2.175. As –2.175 is > |1.96| this mediated effect was significant (p<.05).

This procedure was repeated for maladaptive coping.

1. Linear regression showed that maladaptive a significant predictor of distress with a B coefficient of .474 (standardised β=.410) and this was significant (p<.001). Condition 1 was met.
2. Linear regression showed that maladaptive coping was a significant predictor of RLOC with a B coefficient of -.376 (standardised β=-.468) and this was significant (p<.001). Condition 2 was met.
3. Multiple linear regression was performed with maladaptive coping and RLOC as predictor variables and distress as the dependent variable. RLOC

was a significant predictor of distress with a B coefficient of -.522 (standardised β=-.363) and this was significant (p<.001). Condition 3 was met.

4. The B coefficient for maladaptive coping as a predictor of distress when RLOC scores were controlled for was .277 (standardised β=.240) and this was not significant. Partial mediation has occurred as the B value has decreased but was >0. The amount of mediation was .471-.277=.194.

This shows there is evidence that the relationship between maladaptive coping and distress is mediated by RLOC, with an increase in maladaptive coping associated with a less internal locus of control which in turn was associated with lower distress. This is shown in Figure 4.7

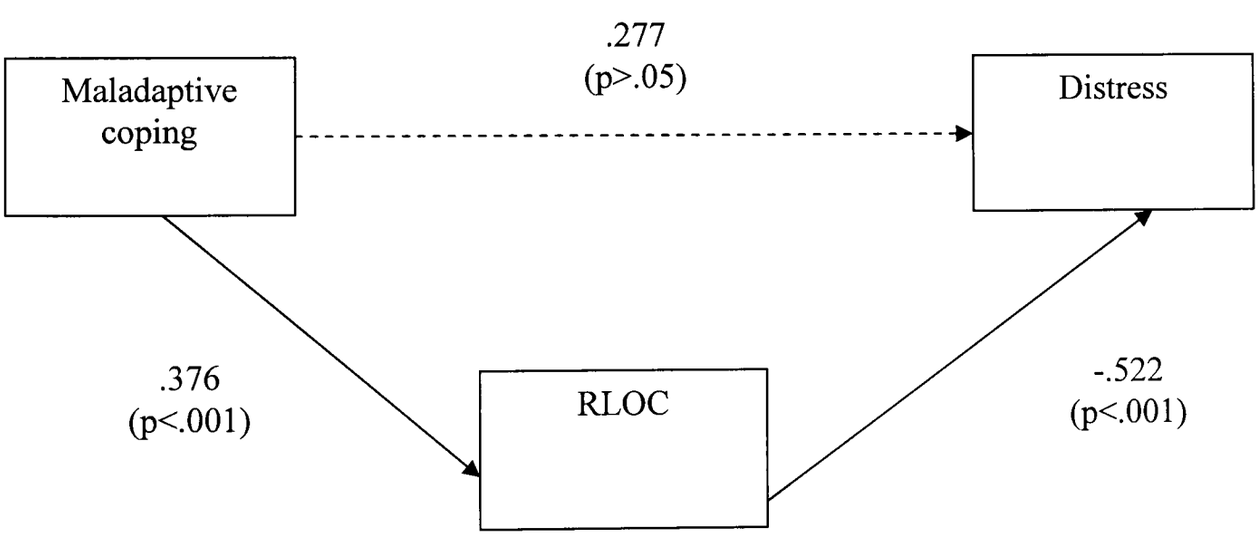


Fig 4.7. Relationship between maladaptive coping and distress at follow up, mediated by recovery locus of control.

The significance of this mediated effect was calculated using the procedure used previously. The z score of the mediated effect was –2.512. As this is > |1.96| the mediated effect was significant (p<.05).

The analysis of follow up predictors of distress at follow up in the sample as a whole showed that Barthel Index scores (categorised as dependent/independent) were not significant in the regression model and further analysis showed that the relationship between the Barthel Index and distress was mediated by EADL. Barthel scores (dependent/independent) were also found to be not significant in the regression model predicting distress at follow up for non aphasic patients. Therefore, analyses was performed to check whether the mediation effect was also present for non aphasic patients. The analysis used the recoded Barthel scores (dependent/independent). This was conducted using the same steps used previously.

1. Linear regression showed that Barthel scores were a significant predictor of distress scores. The B coefficient was –6.562 (standardised β=-.395) and this was significant (p<.001). Condition 1 was met.
2. Linear regression showed that Barthel scores were a significant predictor of EADL scores. The B coefficient was 29.498 (standardised β=.736) which was significant (p<.001). Condition 2 was met.
3. Multiple linear regression was conducted using Barthel and EADL scores as predictor variables and distress as the dependent variable. EADL scores were shown to be a significant predictor of distress when Barthel scores were controlled for. The B coefficient was -.284 (standardised β=-.685) and this was significant (p<.001). Condition 3 was met.
4. Partial mediation was found. Barthel scores were no longer a significant predictor of distress when EADL scores were controlled for. The B coefficient was –1.185 (standardised β=.779) and this was not significant (p=.438). The amount of mediation is –6.562 - - 1.185=-5.377. An increase in

personal ADL is associated with an increase in extended ADL, which is in turn associated with a decrease in distress.

The mediation is summarised in Figure 4.8.

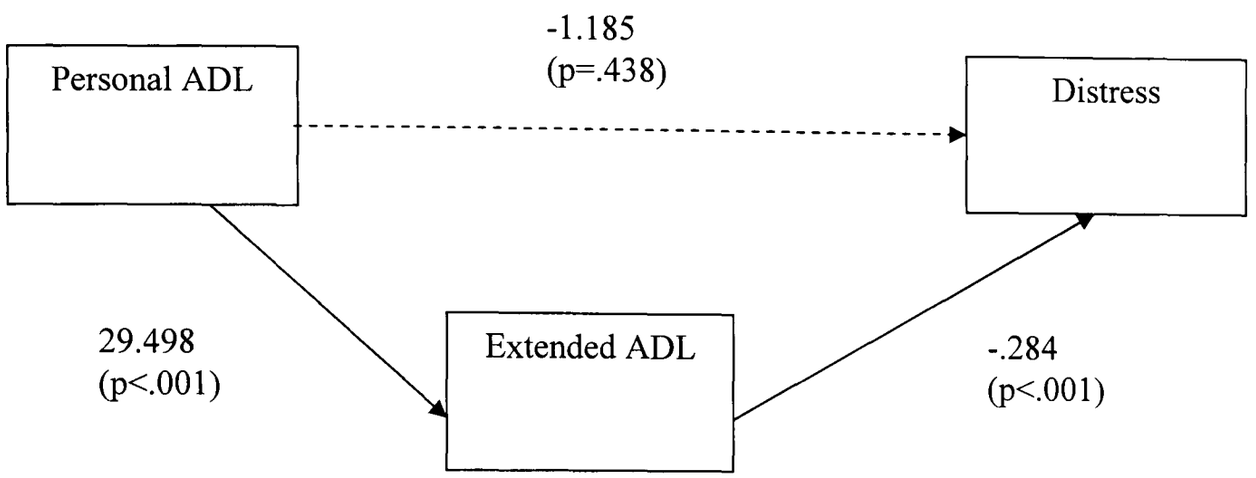


Figure 4.8. Relationship between personal ADL and distress mediated by extended ADL

The significance of the mediation effect was tested. The z score of the mediated effect was 4.298 which is > |1.96| and so the mediated effect was significant (p<.05). This replicates the finding for the sample as a whole at follow up in which the relationship between the Barthel Index and distress (assessed using the VASES-D) was mediated by extended activities of daily living.

4.3.19 Associations between baseline characteristics and follow up distress – non aphasic patients

To develop a regression model to predict HADS distress scores at follow up using baseline assessments and stroke information, associations between baseline information and distress scores at six months were explored. In the analysis looking at follow up predictors of distress at follow up age, gender and martial status were found to be not significant. Independent samples t tests were used to compare categorical variables with two groups and one way ANOVAs were used for

categorical variables with more than two groups. The results are summarised in Table 4.37.

Table 4.37. Comparison between HADS distress scores for baseline categorical variables

Baseline characteristic	HADS distress		
	Mean	SD	p
Living arrangements			
Living alone	8.57	4.80	.484
Living with spouse	8.17	5.71	
Living with son/daughter	2.00	(n=1)	
History of depression	n/a		
Yes	No patients had a history of depression		
No			
Previous stroke			
Yes	9.56	5.45	.585
No	8.43	3.28	
Side of lesion			
Left	7.96	9.29	.327
Right	4.69	5.54	
Bamford classification			
TACS	15.67	2.08	.023
PACS	9.16	5.58	
POCS	6.50	6.50	
LACS	6.76	4.46	

p Probability
SD standard deviation

None of the 73 patients reassessed on the HADS at six months had a history of depression documented in their medical notes. Nine of the patients reassessed on the HADS had suffered a previous stroke. Mean distress scores at six months were slightly higher for patients who had suffered a previous stroke but the difference was

not significant. Distress scores were higher for patients who had suffered a right sided lesion compared to those who had suffered a left sided lesion but this difference was not significant (t_{64}=-.988, p.327). These findings were comparable to those at baseline.

HADS distress scores at follow up were higher for patients who had suffered a TACS compared with those who had suffered a PACS, POCS or LACS and the overall difference was significant. Tukey's post hot test showed that the difference was significant between TACS and POCS ($p<.05$) and between TACS and LACS ($p=.027$) but not between TACS and PACS ($p=.145$). Only three patients assessed on the HADS at six months had suffered a TACS. Bamford classifications were subsequently combined to compared HADS distress scores at six months for patients who had suffered an anterior circulation stroke (TACS or PACS) compared with those who did not (and suffered a POCS or LACS). Distress scores were significantly higher for anterior stroke patients (mean 9.63, SD=5.66) compared with POCS and LACS patients (mean 6.70, SD=4.17) (t_{66}=-2.309, p=.024).

One patient who was living alone with their son/daughter at baseline was reassessed on the HADS at six months and living arrangements at baseline were not significantly related to distress. When the patient who was living with their son/daughter was removed from the analysis, the difference in distress scores at six months between those living with their spouse and those living alone at baseline remained non significant (t_{66}=-.631, p=.530).

Pearson's correlations were calculated between continuous variables assessed at baseline and HADS distress scores at follow up and are shown in Table 4.38.

Table 4.38. Correlations between baseline assessments and HADS distress scores at follow up

	HADS total	
	r	p
Sheffield Screening Test total	-.196	.096
Sheffield Screening Test receptive	-.117	.325
Sheffield Screening Test expressive	-.127	.286
Barthel Index	-.554	<.001***
Pre-stroke Barthel Index	-1.870	.102
Pre-stroke EADL	-1.901	.099
RLOC	-.342	.003**
Adaptive Coping	-.244	.037*
Maladaptive Coping	.370	.001***
HADS total score	.364	.002**
HADS anxiety	.345	.003**
HADS depression	.296	.011*

r Pearson's correlation

p probability level

*** p≤.001, ** p≤.01 *p≤.05

Communication impairment assessed at baseline using the Sheffield Screening Test was not significantly correlated with HADS distress scores at six months. Correlations between the Barthel Index, RLOC, adaptive coping and maladaptive coping were all significantly correlated with HADS distress scores at six months. Greater independence in personal ADL, internality of locus of control and frequency of adaptive coping were all associated with lower emotional distress, while frequency of maladaptive coping was associated with increased emotional distress.

HADS total, anxiety and depression subscale scores at baseline were all significantly correlated with HADS distress scores at follow up, therefore greater distress at baseline was associated with greater distress at six months.

Analysis of baseline results showed that RLOC scores were positively correlated with adaptive coping scores and negatively correlated with maladaptive coping scores. Partial correlations were again conducted. RLOC and follow up distress scores remained correlated when adaptive coping scores were controlled for (r=-.257, p=.029), although the magnitude of correlation was reduced. The correlation between RLOC and distress scores at follow up was no longer significant when maladaptive coping scores were controlled for (r=-.145, p=.225). This indicates that the relationship between baseline RLOC and follow up distress may be partly due to the shared variance in distress scores between RLOC and maladaptive coping scores.

The correlation between baseline adaptive coping scores and follow up distress scores was not significant when baseline RLOC scores were partialled out (r=-.077, p=.519) and the correlation between maladaptive coping at baseline and follow up distress scores failed to reach significance when baseline RLOC scores were controlled for (r=.208, p=.080). This indicates that the relationship between coping strategies at baseline and distress at six months may be attributable to the shared variance in distress scores between coping and RLOC scores.

4.3.20 Baseline factors predicting follow up distress – non aphasic patients

Regression model for predicting follow up HADS distress scores using baseline characteristics

Forward linear regression was carried out to evaluate a model for the prediction of follow up HADS distress scores using baseline assessments. Scores on the Barthel Index. RLOC, adaptive coping and maladaptive coping scores at baseline were all significantly correlated with distress scores at follow up. However, partial correlations showed that the only correlation that remained significant was between RLOC and distress scores when adaptive coping scores were controlled for. Baseline RLOC scores were therefore entered into the regression and this also allows comparison to the baseline regression. Regarding the Bamford stroke classification, as only three patients reassessed with the HADS suffered a TACS, TACS and PACS categories were combined to 'anterior circulation' stroke. These patients had significantly higher distress scores than those who suffered a POCS or LACS. This classification 'anterior' and 'non anterior' was also entered into the regression, which also reduces the number of predictor variables. The results of the regression are summarised in Table 4.39.

Table 4.39. Regression model for predicting follow up HADS distress scores using baseline assessments

	B (95% CI)	SE	Standard-ised B	t	Significance of t	Partial correlation
Barthel	-.594 (-.816- -.37)	.111	-.533	-5.336	<.001***	-.552
Anterior circulation stroke	2.432 (.252-4.611)	1.091	.223	2.229	.029*	.266
RLOC	-.158			-1.478	.144	-.182

CI confidence interval
SE standard error
***p≤.001, *p≤.05

Barthel Index scores at baseline were a significant predictor of HADS distress scores at follow up; greater independence in personal ADL at baseline was predictive of lower emotional distress at six months. Having an anterior circulation stroke was predictive of greater emotional distress at follow up. RLOC scores were not significant in the regression model. The regression model was significant ($F_{2,65}$=18.009, p<.001). The R^2 for the model was .357 and so it accounted for 35.7% of the variance in HADS distress scores at six months post-stroke.

To check that the exclusion of adaptive and maladaptive coping from the analysis was correct, the regression was repeated to include these as predictor variables, but they were found not to be significant (p>.05).

HADS distress scores at baseline were significantly correlated with HADS distress scores at follow up (r=.364, p=.002). A second regression was performed to examine whether baseline distress scores were predictive of follow up distress scores. Baseline distress scores on the HADS were entered into the forward regression in the first step and Barthel, anterior circulation stroke, and RLOC were all entered in the second step. Although anxiety and depression subscale scores at baseline were also correlated with distress scores at follow up, the high correlation between the subscale scores means there would be multicollinearity if both were entered as predictors in the regression analysis, and so they were not included. The results of the regression are shown in Table 4.40.

Table 4.40. Regression model for predicting follow up HADS distress scores using baseline assessments, including baseline HADS distress scores

	B	SE	Standardised B	t	Significance of t	Partial correlation
Barthel	-.505	.131	-.453	-3.865	<.001***	-.438
Anterior circulation stroke	2.503	1.090	.229	2.297	.025*	.278
RLOC	-.153			-1.144	.257	-.143
HADS distress	.0483			.384	.702	.048

CI confidence interval
SE standard error
***p≤.001, *p≤.05

Baseline HADS distress scores were not a significant predictor of follow up HADS distress scores in the regression model. Independence in basic ADL at baseline

assessed using the Barthel Index remained a predictor of lower emotional distress at six months and suffering an anterior circulation stroke also remained a significant predictor of greater emotional distress at six months. RLOC scores at baseline remained non significant. The regression model was significant ($F_{4,63}$=9.622, p<.001). The R^2 for the model was .379 and so it accounted for 37.9% of the variance in HADS distress scores at follow up, this is a marginal increase than the 35.7% found without including baseline HADS scores.

5 CHAPTER 5 - DISCUSSION

5.1 Summary of the study

This thesis was concerned with increasing our understanding of what factors are associated with emotional distress following a stroke, in order to make recommendations regarding therapeutic interventions to treat or prevent emotional distress following stroke. The literature review summarised the main biological (lesion location) and psychosocial characteristics that have been purported to be associated with distress after stroke. This was used to develop a theoretical framework to study emotional distress after stroke. The present study was required as previous research has focused on only a few factors in isolation and has often been exploratory rather than based on theory. Previous studies have also neglected the inter-relationships between constructs. The components of the framework were evaluated in a sample of 100 stroke patients recruited in hospital between two weeks and one month, and who were followed up at six months after stroke onset. All patients were assessed on measures of language, personal and extended ADL and distress, and stroke characteristics were recorded. Patients who were not aphasic also completed assessments of cognitions, recovery locus of control, coping strategies and social support. This section will discuss the findings of the study, in particular considering which factors were associated with distress and the theoretical explanations for this. Limitations of this research will also be considered. Recommendations for psychological interventions to address emotional distress following stroke are outlined.

5.2 Discussion of Findings

5.2.1 Prevalence of depression

The prevalence of depression will firstly be considered. About one-fifth of patients who were not aphasic were depressed on the HADS depression subscale at baseline and a similar rate was found for anxiety on the anxiety subscale. Almost two fifths of non aphasic patients were classified as depressed using the HADS total score. One quarter of non aphasic patients were classified as depressed on the BDI-II, most of these scoring as mildly depressed. The higher rate of depression compared with the HADS may be due to the HADS being designed not to include physical symptoms of depression while the BDI-II contains somatic-affective items. The rate of depression identified using the HADS and BDI-II in this study was reasonably low compared with previous studies which reported between 29% (Berg et al, 2003) and 33% (Knapp & Hewison, 1998; Spencer et al, 1995) of patients were depressed at about one month post-stroke. Astrom et al (1993) assessed patients within the first week of stroke reported that 25% of patients had major depression, which is comparable to the rate using the BDI-II in the present study. Townend (2004) reported only slightly higher mean depression scores on the HADS (4.51 compared with 3.9 in this study). Bennett et al (in press) completed the HADS with healthy elderly people over 55 years and found the median HADS depression score was 2 and 11.8% were classified as depressed. This is lower than in the present study and supports the notion that stroke patients have lower mood than healthy elderly people of a similar age.

The HADS total score provided a higher prevalence of distress than using the depression subscale. This suggests that if we consider emotional distress (symptoms of anxiety and depression) rather than depression defined by exceeding a cut-off

point on a scale then the prevalence of 'emotional distress' is greater than that of a classification of 'depression'. This supports the views of House (1996) and Johnson (1991) who assert that there is an overemphasis on 'post-stroke depression' in the literature rather than consideration of other emotional distress experienced by stroke patients. The high correlations between the anxiety and depression subscales on the HADS supported the use of the total HADS score as a measure of emotional distress.

There are two possible explanations for the low rate of depression in the present study. Patients were recruited between two weeks and one month after stroke. It is possible that initially patients may be unrealistic and optimistic concerning their perceived recovery. Secondly, this finding may be due to self-selection bias whereby those patients who have low mood declined to participate and the reasonably high rate of refusal supports this. The prevalence of depression at follow up was similar to baseline, suggesting that emotional distress remains an important issue at six months post-stroke. Also, patients who scored high on distress at baseline remained highly distressed at follow up, demonstrating that distress is persistent and that there is a need to consider interventions early after stroke to prevent distress persisting.

The proportion of non aphasic patients classified as depressed on the HADS depression subscale increased from 21% at baseline to 25% at follow up, but this difference was not significant. This prevalence rate is higher than the 20% reported by Dennis et al (2000) who used the same assessment at six months. Dennis et al (2000) recruited patients for a randomised controlled trial (evaluation of a stroke family care worker), included patients not admitted to hospital and did not assess mood before six months. Also, patients considered unlikely to survive or had a

comorbid illness that may dominate care were excluded. The higher rate of depression found in the present study may be attributable to the fact that broader inclusion criteria were used and patients were recruited from hospital. BDI-II scores were non significantly lower at follow up. This may be due to the somatic items being less relevant later than in hospital, for example sleep and appetite can be influenced by hospitalisation. The prevalence of anxiety was non significantly lower at six months. Anxiety may have been higher in hospital where there is uncertainty about the rate and extent of recovery. From discussions with patients in hospital it was apparent that the greatest anxiety was whether they would be able to go home, when this would be, and what arrangements were needed for this.

Observed ratings of mood for all patients were collected using the SADQ-H (11 were not returned at baseline). Just over one-third of patients met the cut-off for depression. The higher rate of depression identified using the SADQ-H compared with the HADS and BDI-II suggests that observed behaviours may be less specific indicators of distress. It is also possible that observer behaviours in hospital are attributed to mood. However, the SADQ-H would be informative in clinical practice to identify which patients require a more detailed assessment of mood.

Discussion is required regarding the measures of emotional distress used. There were intercorrelations between the visual analogue and observer-rated measures and well established measures of mood (HADS and BDI-II) which provided evidence for concurrent validity. The internal consistency of the VAMS has been found to be higher when the happy and energetic items are removed (Bennett et al, in press) and this was supported in the present study. Happy and energetic are the only two

positively worded items. It is possible that patients developed a tendency to mark towards the top of the vertical line (near the neutral face) even when the emotion face was positive. The internal consistency of the VAMS may increase if the direction of the presentation of the two positive items are reversed, such that 'happy' and 'energetic' faces are at the top of the vertical line so this direction is always positive. Further studies would be required with stroke patients to validate this. The internal consistency of the VASES has been found to be higher when the depression item (the practice item) was included in the total score (Bennett et al, in press). The significant correlation between the VASES-D and the other mood measures in this study suggests that the VASES-D functions as a measure of distress.

Patients classified as 'aphasic' using the Sheffield Screening Test were compared with the non aphasic patients on the VASES-D and VAMS-HE. Aphasic patients scored as more distressed than non aphasic patients on the VASES-D and VAMS-HE at baseline and follow up. Distress in aphasic stroke patients has not been widely studied and such patients are usually excluded. The findings from the present study support the literature that reported depression and low mood to be common in patients with aphasia (Kauhanen et al, 2000; Astrom et al, 1993; Thomas & Lincoln in press). Astrom et al (1993) found aphasia to be associated with an increased risk of depression in the first week of stroke, and the present study extended this finding to the first six months after stroke. Many everyday functions and activities rely on communication, such as conversation, reading and socialising, and so the impact of aphasia may have detrimental effects on mood and self-esteem. The behavioural theory explanation of this is that reduced interactions with others and the world around them results in reduced positive reinforcement and positive feedback from

others. The finding that emotional distress was more common in patients with aphasia provides further evidence that such patients should not be excluded from research into distress after stroke. Moreover, staff working with patients with aphasia should be aware that these patients are vulnerable to distress and this should be monitored.

The Stroke Cognitions Questionnaire Revised (SCQR) was developed as part of this thesis. SCQR scores were significantly correlated with the HADS and BDI-II, meaning that a greater frequency of negative cognitions and a lower frequency of positive cognitions were associated with lower mood. These findings replicate the validation work on the scale and provides further support for the cognitive model of depression (Beck, 1976, 1987) in which depression is characterised by negative thoughts and a decrement in positive thinking. One previous study with stroke patients found a non significant trend towards a negative cognitive style and negative cognitions in depressed patients (Noble, 1993). However, this was based on a small domiciliary sample. The present study was longitudinal and so provided some evidence for the cognitive theory of depression in the acute and chronic stages after stroke. Also, the SCQR scale was developed from treatment notes of depressed stroke patients receiving cognitive behaviour therapy and so would be expected to provide a more relevant assessment of stroke-related cognitions.

5.2.2 Discussion of factors associated with emotional distress

This section will summarise the main findings of factors found to be predictive of distress and then consider explanations for these. For the whole sample, impairment in expressive communication and dependence in personal activities of daily living (ADL) at baseline were predictive of distress at baseline. At six months follow up

expressive communication and dependence in extended ADL at follow up were predictive of distress. The relationship between personal ADL and distress was mediated by extended ADL. In the sample of non aphasic patients recovery locus of control, communication impairment and dependence in personal ADL were predictive of distress at baseline. At follow up dependence in extended ADL, actual practical social support and recovery locus of control were significant predictors of distress at follow up. At both baseline and follow up the relationship between adaptive and maladaptive coping and distress was mediated by recovery locus of control. This section will now explore explanations for these findings.

Expressive communication impairment was a significant predictor of distress both at baseline and follow up for the whole sample. Receptive communication may not have been associated with distress as patients with poorer receptive communication abilities may have less understanding of the impact of stroke. This is supported by Herrmann et al (1993) who found depression severity to be greater in those with nonfluent aphasia compared with fluent aphasia. Overall communication impairment in non aphasic patients was also predictive of distress at baseline and at follow up. The range of scores on the Sheffield was quite narrow in this group as patients had scored above the cut-off. Therefore, findings indicate that even mild communication impairment is associated with distress early after stroke, as perhaps this makes interacting with others more difficult.

Aphasic patients are usually excluded from studies of distress after stroke which makes comparison to the literature difficult. Also, those studies which have included aphasic patients, such as Astrom et al (1993), have not assessed the severity of

communication impairments. This is one of the strengths of the present study as it did assess communication impairment. Severity of aphasia has been found to be related to the amount of time spent in social activity (Code, 2003). It is possible that patients with more severe expressive aphasia were less able to interact with others and participate in activities. Consequently such individuals may receive less reinforcement and experience feelings of failure if they are unable to communicate with others, which in turn may lead to low mood as would be predicted by the behavioural model of depression (Lewinsohn, 1974; Lewinsohn et al, 1985). Time sampling studies of stroke patients showed that majority of time was spent in passive, solitary activity (Bernhardt et al, 2004; De Wit et al, 2005; Keith, 1980; Keith & Cowell, 1987; Lincoln et al, 1989; Lincoln et al, 1986). However, these studies did not examine separately patients aphasic and non aphasic. To explore whether aphasic patients have lower mood as a result of reduced interactions with others, time sampling studies should record communication impairment and any other impairments that may make interacting with others difficult, such as mobility. It is also possible that communication impairment may have affected marital relationships, but carer characteristics were not assessed to explore this.

Communication impairment remained an important factor predictive of distress at six months. Herrmann et al (1993) also found depression to be equally as common in patients with acute and chronic aphasia. An explanation for sustained importance of expressive communication impairment is that when patients have been discharged the impact of the stroke and communication difficulties on everyday life becomes evident. The major prognostic factor for recovery of communication is initial loss

(Wade et al, 1985) and so greater communication impairment at baseline may be related to distress at six months due to less improvement in communication.

It is possible that performance on the Sheffield Screening Test was affected by cognitive impairment. For example, Al-Khawaja and Wade (1996) found Sheffield Screening Test scores to be correlated with the Short Orientation, Memory and Concentration Test in stroke patients on a rehabilitation unit. This implies that further investigation of the relationship between communication impairment and distress could include an assessment of memory or cognitive function. The Sheffield Screening Test was included in this study as a brief screen for language disorders as it was suitable for the researcher who was a psychologist. A more detailed assessment of language is required to identify if there are relationships between more specific components of communication impairment and mood.

Activity level in the form of personal and extended ADL was associated with distress. Dependence in personal ADL was a significant predictor of emotional distress at baseline in the whole sample and for non aphasic patients. Kellerman et al, (1999), Ng et al (1995) and Wade et al (1987) also found dependence on the Barthel Index to be related to mood within the first month after stroke. Dependence on others for personal ADL may promote feelings of helplessness and reduced feelings of mastery and success, which result in low mood. Negative reinforcement may also be experienced following 'failure' such as not achieving a recovery goal the patients have set themselves.

Dependence in extended ADL at follow up was predictive of distress at follow up for the whole sample of patients and also non aphasic patients. Most studies have only assessed personal ADL, therefore the inclusion of the EADL scale was informative. There is some evidence in the literature that dependence in EADL is related to distress as the Functional Independence Measure (van de Weg et al, 1999) and the Frenchay Activities Index (Wade et al, 1987) have been found to be correlated with mood at six months.

Extended ADL at follow up were a significant predictor distress at follow up but personal ADL were no longer significant in the regression model. The relationship between the Barthel Index and distress was mediated by EADL, whereby the dependence on the Barthel was associated with greater dependence in EADL which in turn was associated with greater emotional distress. This is comparable to Wade et al (1987) who found that the relationship between Barthel and mood at one year post-stroke was mediated by scores on the Frenchay Activities Index. This provides some evidence for the activity restriction framework (Williamson, 1998) whereby major disruption in normal activities can result in poorer mental health outcomes. Moreover, the integrative model of depression (Lewinsohn et al, 1985) predicts that a stressor will be an antecedent to depression to the extent that everyday and important behaviour patterns are disrupted, due to decreased positive reinforcement, self-criticism and negative expectancies. This suggests that it is not the level of disability per se that is important but rather the extent to which the disability influences participation in extended ADL that is important. This may be because after discharge when many patients have returned home, the impact of their disability on performing everyday activities becomes apparent.

At six months those patients living in a nursing home had significantly higher levels of distress (VASES-D) than those who were not living in a nursing home in the whole sample. This supports the findings of Sharpe et al (1994) who reported that living in an institution at three to five years post-stroke was associated with depression. Further analysis in the present study indicated that this relationship was likely to be because patients living in a nursing home were more disabled. However, only six patients lived in a nursing home at follow up and so further exploration of this factor was not possible.

Recovery locus of control (RLOC) was a significant predictor of distress scores at baseline and at six months post-stroke. This replicates previous studies that have assessed the relationship between these constructs (Beekman et al, 1998; Johnston et al, 1999). It was suggested that an internal locus of control is associated with increased acceptance of disability (Martz et al, 2000). An individual with a more external locus of control perceives that they have little control over their recovery and that others are responsible for and have control over their recovery. This may cause an individual to believe that they are not very good at something, or that their efforts are not of greater importance in their rehabilitation. Consequently, they may have increased feelings of helplessness and take a less active role in their rehabilitation, resulting in reduced reinforcement as predicted by the behavioural model of depression. It should however be noted that the distribution of RLOC scores were negatively skewed, with the mean score indicating that most patients had an internal locus of control.

Adaptive and maladaptive coping scores were both significantly correlated with distress scores: an increase in adaptive coping was associated with lower distress and conversely an increase in maladaptive coping was associated with greater distress. This relationship was found both at baseline assessment at six months, therefore the finding was consistent in hospital and after discharge. Adaptive coping items included taking action to make the situation better, getting help and advice and looking for something good in what was happening. This may be associated with lower distress as people may address problems and improve the person-environment relationship (Lazarus & Folkman, 1988). Maladaptive coping included refusing to believe what has happened, giving up trying to deal with the stroke, being self critical, self-blame and distraction. Maladaptive coping may be associated with expectations of helplessness and consequently lower mood (Rosenberg et al, 1987). Previous studies have also found maladaptive coping strategies to be associated with depressed mood in stroke (Rochette & Derosiers, 2002; Finset & Andersson, 2000; King et al, 2000), spinal cord injury (Kennedy et al, 2000) and myocardial infarction (Lowe et al, 2000), indicating that this relationship may not be specific to stroke.

Previous studies have assessed either coping or RLOC in isolation but have not considered whether there may be an association between them. This study assessed both coping and RLOC which enabled this relationship to be explored. At both baseline and follow up assessments, the relationship between adaptive coping and distress and between maladaptive coping and distress was mediated by RLOC Therefore, an increase in adaptive coping led to a more internal locus of control which in turn led to a decrease in distress. Adaptive coping concerns efforts to do something about the situation you are in which may increase feelings of control if i

is perceived to be successful. Boynton et al (1994) suggested that problem-focused coping as it may be associated with an increased sense of self-control. This is an interesting finding and has important implications for developing interventions as it implies that, rather than aiming to modify locus of control, efforts should be aimed at increasing adaptive coping strategies in order to influence locus of control and subsequently mood.

The finding that LOC mediated the relationship between coping and distress is perhaps contrary to prediction as it is suggested that coping is determined by mental representations or appraisals, such as control (Johnston et al, 1999). It was expected that an internal locus of control would be associated with more effective coping and better adaptation to disability as individuals believe they are able affect the situation they are in (Maas et al, 1988). Stable factors that are coping resources may influence coping behaviour, such as generalised control beliefs (Terry, 1994). For example, Johnston et al (1999) proposed that appraisal of control may be associated with the engagement in exercise which in turn influences disability level. However, they found that engagement in exercise at one month post discharge was not significantly correlated with recovery locus of control. One explanation for the differing finding in the present study is that previous literature has referred to generalised control beliefs as a stable factor. However, the present study assessed recovery locus of control which was found to be influenced by the situation, as locus of control beliefs were significantly more internal at six months post-stroke compared with one month. As outlined in the literature review, the process of coping consists of primary appraisal, secondary appraisal and coping (Lazarus & Folkman, 1984). These processes are evolving and do not necessarily occur in an unbroken linear sequence. This means

that it is difficult to study the relationship between recovery locus of control and coping as this may be dynamic and so the data collected in this study may refer to a 'snapshot' of this process and thus an oversimplification of what is occurring. It should also be acknowledged that in mediation analysis there might be other models that are consistent with the data (Frazier et al, 2004).

Recovery locus of control at baseline was also significantly associated with distress at follow up, with internality of locus of control correlated with lower distress, but this was not significant in the regression model. This replicates the findings of Morrison et al (2000). They suggested that other factors may need to be assessed, such as self-efficacy, which is the individual's belief in their capability to do what is required to be in control (Morrison et al, 2000). In contrast to the findings in Chapter 4, the secondary analysis of data from a CBT trial presented in Chapter 3 found that RLOC scores at initial assessment (when patients were one to six months post-stroke) were a significant predictor of depression at the follow up assessment (when patients were seven to 12 months post-stroke). This discrepancy may be attributable to different characteristics of the samples. In Chapter 3 all patients were depressed when recruited, RLOC scores were more external and these were similar at baseline and follow up. In Chapter 4 both depressed and non depressed patients were recruited, RLOC scores were more internal and significantly increased over time. As RLOC scores changed over time, possibly because patients had been discharged from hospital by the follow up assessment, RLOC at the initial assessment was not an important predictor of later distress.

Coping strategies assessed within the first month after stroke were not significant predictors of emotional distress at six months. Appraisal and coping are dependent on the situation (Folkman & Lazarus, 1988). It is likely that recovery locus of control is affected by the hospital environment and that coping strategies are influenced by the stressors that the individual encounters. The dynamic nature of recovery locus of control and coping may account for why these factors assessed at baseline did not predict distress at six months.

Actual amount of, and satisfaction with, emotional and practical social support were significantly correlated with distress at six months, but the only aspect of social support that was a significant predictor of distress at six months was the amount of practical support. Higher levels of practical support were associated with less distress. Previous studies also found the amount of support and satisfaction with support to be correlated with mood (King et al, 2002; Friedland & McColl, 1987; Morris et al, 1991; Spencer et al, 1995). High levels of practical support may be important as practical assistance such as help with domestic and everyday tasks may be relevant when patients are at home. This support could influence the appraisal of the stressor and can provide coping resources (Lazarus & Folkman, 1984). This in turn may have a favourable effect on mood as practical support can help address problems causing distress and can improve the person-environment relationship (Lazarus & Folkman, 1988).

Satisfaction with the amount of emotional and practical support were not significant predictors of distress at six months. The mean level of discrepancy of one point (on a scale of 7) indicates there was little discrepancy between received and ideal levels of

support, therefore patients were generally satisfied with the level of support they received, although it remains possible that patients were reluctant to report dissatisfaction with the support. The measure of social support used was brief and only assessed emotional and practical support, each using two items. Informational or guidance support were not measured. However, the assessment was considered appropriate as it provides scores of actual, ideal and satisfaction with support and it is simple for patients to complete.

Anterior circulation stroke (TACS or PACS) and greater dependence in basic ADL assessed within the first month post-stroke were significant predictors of emotional distress at six months post-stroke for non aphasic patients. It is likely that there is some overlap between the two predictors due to TACS and PACS being associated with greater disability. Dennis et al (2000) also found that anterior circulation stroke was a significant predictor of distress (HADS depression score) at six months post-stroke. This is consistent with evidence that greater lesion volume is associated with the presence and severity of distress (Shimoda & Robinson, 1999; MacHale et al, 1998; House et al, 1990; Sharpe et al, 1990; Eastwood et al, 1989; Sinyor et al, 1986; Robinson et al, 1984). Lesion volume was not assessed directly in the present study but TACS and PACS stroke lesions are expected to be larger than LACS or POCS (Mead et al, 2000).

For the whole sample, when baseline distress scores were entered into the regression prior to the other variables the model explained just over two-fifths of the variance in distress scores and this increased to over half when the Sheffield expressive scores and Barthel scores were entered. Therefore, for the whole sample the most important

predictor of distress at six months was emotional distress at one month. This concords with the finding that there was no significant difference in VASES-D scores at baseline and follow up and demonstrates that distress at one month post-stroke is persistent. Few longitudinal studies have been conducted to examine predictors of distress. Depression early after stroke has also been reported to be predictive of depression at about six months post-stroke (Spencer et al, 1995), one year and 18 months post-stroke (Berg et al, 2003), and two years post-stroke (King et al, 2002). In contrast to the previous studies mentioned the present study included patients with aphasia. However, for patients without communication impairment, baseline distress scores were not a significant predictor of distress at six months. The finding was slightly unexpected as there was no significant difference between baseline and follow up distress scores and the scores were significantly correlated, although the magnitude of this correlation was low. One reason for this may be that dependence in personal ADL and distress were correlated at one month, indicating that this was a more important predictor of distress at follow up at six months for non aphasic patients.

At baseline the regression model for the whole sample accounted for about one quarter of the variance in distress scores. Therefore, the relationship between communication impairment, dependence in personal ADL and distress is likely to be more complex and other factors may be important. For example, locus of control and coping strategies may be relevant but this could not be assessed in patients with communication impairment and no suitable measure for these patients is available. For non aphasic patients the model containing communication impairment, personal

ADL and locus of control accounted for just over half of the variance in distress at baseline.

At follow up the regression model for the sample as a whole containing expressive communication and EADL accounted for about one third of the variance in distress. In the sample of non aphasic patients, EADL, actual practical social support and recovery locus of control accounted for just over half of the variance in distress. The proportion of variance in distress accounted for by the models in the present study is comparable to regression models in the literature which accounted for between 11% (Herrmann et al, 1998) and 60% (Wade et al, 1987) of the variance in distress scores in the first year after stroke. The models for the whole sample may have accounted for less variance in distress than the models for non aphasic patients as fewer assessments could be completed with aphasic patients. The factors assessed in this thesis were based on a theoretical rationale. Studies with stroke patients are limited by the number and nature of assessments that it is reliable to complete, therefore the present study focused on those psychosocial variables argued to be associated with distress and that which could be amenable to psychological intervention. It is possible that other factors may account for some of the variance in distress and these are considered in the discussion of methodology.

Similar factors were predictive of distress at baseline and at follow up which indicates that distress early after stroke and later after stroke is aetiologically similar rather than two distinct conditions. This is in contrast to the Herrmann and Wallesch (1993) who suggested that organic factors, namely lesion location, are important in the acute stages after stroke and that psychological factors are important later on,

although they did not describe in detail the role of these factors. The theoretical framework for this thesis proposed that psychological factors were important in the development of distress after stroke and this was supported by the finding that recovery locus of control, coping and social support were associated with distress. This is also in accordance with Gainotti et al (1999) who argued that depression was a psychological consequence of stroke. Communication impairment and activity level were predictive of distress. This can be explained by the behavioural model of Lewinsohn et al (1985) who proposed that negative emotional reactions result when a stressor disrupts everyday behaviours and interactions that would have provided positive reinforcement. Support was found for the theoretical framework proposed in this thesis, as communication impairment, dependence in personal and extended ADL and psychosocial variables were related to distress. However, mediation relationships were found between personal and extended ADL and distress, and between coping, locus of control and distress. Also, the only aspect of social support related to distress was actual practical support. To provide a more comprehensive account of distress after stroke the framework would need to be modified to incorporate these findings. Also, the results suggest that demographic and background characteristics are not important in a predictive model of distress, which was proposed in the outline of the theoretical framework.

The only significant variable predictive of distress on the SADQ-H was the Barthel Index at baseline and the EADL at follow up. Activity level only accounted for 5% of the variance in SADQ-H scores. This may be because the items on the SADQ-H refer to the behavioural (observed) symptoms of low mood. It is possible that some

of the items on the SADQ-H may reflect dependence, for example the patient may be unable to do things to initiate activities.

5.2.3 Differences in assessments between baseline and follow up

There was a significant increase in independence in personal ADL at six months and a ceiling effect was found. This was expected as most recovery of ADL function occurs in the first three to six months, with the ceiling effect as most ADL scales saturate at the upper end of the range (Wade et al, 1985). Similarly, scores on the Sheffield Screening Test significantly increased at six months indicating less communication impairment and Wade et al (1985) stated that spontaneous recovery of aphasia is fastest in the first few months. These findings therefore fit with the recovery of ADL and communication in the first six months post-stroke.

There were changes in scores on the psychosocial variables at six months which suggests that recovery locus of control (RLOC) and coping are not stable and they may be state characteristics rather than traits. RLOC scores became significantly more internal at follow up. It is likely that perceptions of control are influenced by the hospital environment. In hospital the patient were receiving therapy and a lot of assistance and support from hospital staff. Also, the hospital environment conferred little control for the patient. This may explain why perceptions of control were more external in hospital. After discharge the patient may have realised that the hospital staff were no longer responsible for their daily care. Information was not recorded regarding what care patients were receiving after discharge and so it could not be analysed to determine whether this affected perceptions of control.

Adaptive coping strategies were reported more frequently and maladaptive coping strategies reported less frequently at six months compared to baseline. This may be related to the corresponding increase in internality of locus of control at follow up, as individuals with an internal locus of control are likely to take control of their situation (Wallston & Wallston, 1982), while an external locus of control is associated with passivity (Blair et al, 1999). Also, coping arises during a stressful encounter and can vary according to the situation the individual is in. This means that adaptive coping strategies may be more relevant when patients have been discharged and they have to cope with the effects of the stroke on their everyday lives, without the support of the hospital environment.

5.2.4 Factors found not to be associated with emotional distress

Demographic factors (age, gender and living arrangements), medical comorbidities and lesion laterality were not significantly associated with distress at baseline or follow up assessments. This section will consider explanations for these findings.

5.2.4.1 Demographic factors

Age was not significantly correlated with emotional distress. This is in accordance with a majority of studies in the literature review. Most patients in the present study were around 70 years old; there were fewer patients younger than retirement age and the oldest patient was 86 years. Age may have been unrelated to emotional distress in this sample due to the "social clock" (Neugarten et al, 1996). As most patients were just over the age of retirement, the occurrence of a chronic illness is more expected than at a younger age (Neugarten et al, 1996). However, patients who declined to take part in the study were significantly older than those who did participate, and so the sample was not fully representative of the whole age range of stroke patients.

There was no significant difference in the emotional distress reported by men or women at baseline or follow up assessments. This supports most studies in the literature review which found that gender was unrelated to distress and these studies assessed patients up to three years post-stroke. There was a trend in some studies for women to be at a greater risk of distress. It is not clear why findings are inconsistent across studies, however comparisons are made difficult by the heterogeneous methods, such as inclusion criteria, assessments and timing of assessments. Burvill et al (1997) found men under sixty were more likely to be depressed, as were women in the older age group. As the age distribution in the present study was quite narrow, this precludes a more detailed examination of any interaction between gender and young (i.e. under 50 years) and very old (i.e. over 85 years) ages.

Just over half of the patients were married and living with their spouse. Marital status and living arrangements were not associated with emotional distress at baseline or follow up. This is consistent with the literature review. The impact of stroke on marital relationships was not assessed, nor was carer strain, and it is possible that the quality of the relationship may be relevant. The findings at follow up that satisfaction with social support was related to distress suggests that the overall social support network available to the patient is more important than the presence of a spouse.

Most patients were retired which is not unexpected given the mean age of the sample. Employment status was unrelated to emotional distress which concords with the finding that age was not related to distress. Employment status has not been widely studied. It is possible that employment status is a more pertinent factor in younger patients who do not return to work following their stroke as this would be

expected to have a major impact on their everyday life and financial status, but this could not be explored in the present study sample as most patients were retired.

In summary, there was no evidence for a significant relationship between demographic characteristics and emotional distress following stroke. Those studies in the literature that did find these factors to be significant, they did not account for a large proportion of the variance in distress. This suggests that factors other than demographic characteristics are important, such as disability and psychosocial variables. This finding is important as demographic factors cannot be modified, therefore those factors associated with distress may be amenable to intervention.

5.2.4.2 Medical comorbidities

Personal history of depression was unrelated to emotional distress at baseline and follow up. This is in accordance with a majority of studies in the literature review and suggests that the prevalence of distress was not overestimated by including patients with a history of depression. However, as a pre-stroke history of depression was only documented in the medical notes for four patients it is difficult to draw conclusions. In contrast to the present study, some studies reported a personal psychiatric history to be related to depression following stroke. Conflicting findings may arise from heterogeneity in methods used to define and assess psychiatric history, as identified by Spencer (1997). The limitations of the method used in this study is considered in the discussion of methodological issues.

Having a previous stroke was not associated with distress at baseline or follow up. Such patients are frequently excluded from studies of post-stroke distress and those studies that have included them reported mixed findings. Studies which have

included patients who suffered a previous stroke have not recorded residual disability, as the severity of the previous stroke may be relevant. In the present study patients who had suffered a previous stroke and whose subsequent stroke was severe may have died before one month post-stroke or were too ill to assess. Pre-stroke Barthel scores were unrelated to distress, although there was a ceiling effect. Fourteen patients had had a previous stroke, which means that the exclusion of patients with previous stroke would have not been representative of the population in the hospitals in the present study. It is unrealistic to try and create an homogeneous sample, for example by excluding those with a previous stroke and a history of depression, as this would leave sample of patients that is not representative of the stroke population.

5.2.4.3 Stroke characteristics

Side of stroke lesion recorded from the CT scan was unrelated to distress at baseline or follow up. This is in accordance with a majority of studies identified in the literature which found no support for an association between hemispheric side of lesion and mood. This is also supported by a review (Singh et al, 1998) and a meta-analysis (Carson et al, 2000). It is likely that the relationship between side of lesion and distress is too simplistic and that the impairments caused by a lesion may be more important. For example, presence and severity of communication impairment were related to emotional distress in the present study. This has more relevant clinical implications in identifying patients at risk of distress, as it is both more clinically relevant and practical to assess a patient for an impairment (for example, communication) than to take detailed measurements from a CT scan, which should be performed early after stroke.

The Bamford stroke classification was used in the present study rather than a measurement of lesion location. The limitations of not measuring lesion location are considered in the discussion of methodological issues in this chapter. However, the present study was not designed to test lesion location in detail and measurement of lesion location from CT scans do not reflect clinical practice. At baseline the Bamford classification was not associated with emotional distress assessed using the VASES or SADQ-H. TACS patients had significantly higher levels of distress measured using the HADS than patients classified as PACS, POCS or LACS and this replicates the findings of Dennis et al (2000). This may be because TACS indicates a larger lesion and Barthel scores were lowest in TACS patients. In the regression model the Bamford classification was not a significant predictor of emotional distress at baseline while the Barthel Index was. This provides support for the assertion that it is not the characteristics of the lesion that are important, but rather the impairments caused by the stroke.

5.3 Methodological issues

It is important that the findings of the study are considered in the context of the methodologies used. The methodological issues arising with this study will be discussed as these may affect the generalisability of the findings. Practical and methodological issues arise when conducting research with stroke patients, and it is important to consider the findings and conclusions of this thesis in this context. For example, it is common for individuals to have poor concentration, memory difficulties and be easily fatigued following stroke. This means that assessments can be tiring for patients and may need to be completed over several sessions. These factors constrained the number of assessments that could be administered, and was taken into account when choosing assessments to include. Justification of the study

design, methodology and assessments used was provided in the Method chapter. However, the effect of the methods on the study findings will be discussed.

5.3.1 Methodologies used

Self-report measures and an observer-rated scale were used to assess emotional distress, rather than a structured diagnostic interview, as the present study was concerned with assessing the severity of distress rather than providing a diagnosis of depression. The self-report measures of distress used in this study have previously been used with stroke patients and justification for these choices was detailed in the Method chapter. High concordance was found between the self-report scales of distress in this study, and between the self-report (BDI-II and HADS) and observer scale (SADQ), and the cut-offs used in this study to classify patients as 'depressed' were selected by reviewing cut-offs used in other stroke studies. Interviews to provide ICD-10 or DSM-IV diagnoses require training and are more time consuming to conduct, and were not routinely employed in the hospitals in this study. The use of self-report scales was a more accurate reflection the assessments used on hospital wards, however, the limitations of this method are acknowledged.

Lesion information collected in the present study was the side of lesion from CT scan reports and the Bamford stroke classification documented in hospital medical notes. Therefore the lesion findings from this study cannot be directly compared to studies which have used the classification of Robinson et al (1984). The criticisms of Robinson's classification were discussed in the literature review. The Bamford classification is more relevant as it is linked to the clinical features of the stroke in comparison to an arbitrary distinction between anterior and posterior lesions.

Moreover, the ward staff in the hospitals routinely documented and referred to the Bamford classification in the medical notes.

A detailed description of pre-stroke history of depression was not collected. Information regarding depression history was recorded from hospital medical notes. This would have only recorded previous depression if it was severe enough to require treatment It is possible that not all previous episodes of depression were recorded in the medical notes, this may have been why a history of depression was uncommon. It is also possible that some patients had undiagnosed or untreated depression. No consistent method has been adopted in the literature (Spencer et al, 1997). G.P. notes could have been consulted, but this would have been time consuming and the accuracy and detail likely to be variable. A complementary method would have been to ask the patient about previous depression and to interview a carer/relative, but not all patients had someone appropriate to ask (and this assumes they were aware of prior depression), and it is not known how reliable this would have been.

The findings may not be specific to stroke as a comparison group of people with other neurological conditions or comparable disabilities was not included. Therefore, the prevalence of distress and the psychosocial constructs assessed could not be compared to a group of equivalent age and disability. The aim of the study was to evaluate the components of the proposed theoretical framework of emotional distress in stroke patients, but it cannot be concluded that the overall findings are specific to stroke. For example, coping strategies have been found to be related to mood in spinal cord injury patients (Kennedy et al, 2000) and in patients who have suffered a myocardial infarction (Bennett et al, 1999; Lowe et al, 2000), and externality of

locus of control was related to distress in spinal cord injury patients (Macloed & Macleod, 1998). The reason for wanting to compare risk factors for distress in stroke to other populations are that interventions to treat distress in non stroke populations may inform appropriate interventions in stroke. However, it is not always appropriate to make comparisons to other patient groups as different assessments may be used that are specific to the population. Previous studies have used gender- and age-matched controls from the same geographical area as the stroke sample (Burvill et al, 1995; House et al, 1991), but it is difficult to identify an appropriate control group of a similar age with comparable disabilities. The present study was not developed to examine the specificity of risk factors for distress to stroke patients.

5.3.2 Psychological aspects of assessment

A battery of questionnaires was chosen to collect a majority of the data in the present study. This was the most appropriate method for assessing psychosocial constructs such as locus of control, coping strategies and social support, as reported by the patient. The researcher completed the assessments with the patient, reading aloud questions and responses if required, in order to reduce missing data. In contrast House et al (1991) required patients to complete the Beck Depression Inventory (BDI) by themselves rather than by interview. However, they found that some patients were unable to complete the BDI. Therefore it was considered that the researcher completing the BDI-II with the patient was appropriate. Self-report assessment methodology relies on the patient providing reliable responses. It is possible that some patients deny symptoms or low mood which has been suggested to be a source of measurement error (Ketterer et al, 2004). The SADQ-H was included as an observer rating of mood which correlates with self-reported mood in previous stroke research (Lincoln et al, 2000) and in the present study.

Constructs from social psychology concerning the interaction between the researcher and participant may influence patient's responses. Social desirability refers to participants wanting to be seen in a positive light, and so they may be reluctant to provide honest reports of qualities that they think may be regarded negatively (Manstead & Semin, 1996). In the context of the present study it is possible that patients may not have wanted to report depression symptoms or coping strategies considered to be negative. In order to try and reduce this, the researcher, in accordance with ethical guidelines, assured the patient that their participation in the project was voluntary and that all responses were kept confidential, but it is not know whether this reduced social desirability.

Responses may also have been affected by interviewer effects, whereby the investigators' hypothesis or expectations unintentionally influenced their behaviour towards participants in such a way to confirm their hypothesis. Interviewer effects were reduced in the present study through the use of assessments with standardised administration and by selecting scales with good inter-rater reliability. An alternative method would have been to send questionnaires postally. Parker and Dewey (2000) posted outcome questionnaires to participants of a randomised controlled trial (RCT) of occupational therapy and leisure after stroke. The initial response rate was 60% which increased to 85% following reminders. However, 43% were incomplete and patients were subsequently contacted by telephone for missing responses. It would not have been possible to ensure that patients completed the questionnaires themselves. Also there may be an increased risk of patients becoming upset if mood questionnaires were completed over the telephone rather than face to face.

There are also neuropsychological concepts that may affect patients' ability to reliably report their mood. For example, lateralisation of the stroke lesion may affect the expression of emotion or affect. *Alexythymia,* which is a difficulty in identifying and describing emotions, has been found to be more common in patients with right-hemisphere lesions compared to left hemisphere lesions (Spalletta et al, 2001). However, in this study self-report measures had multiple response options and so patients were not required to give descriptions of their emotions, and lesion laterality was unrelated to distress. While some patients may be unable to describe their emotions, others may be unaware of their emotional state. *Anosognosia* is the complete or partial unawareness of a deficit (Carota, Staub, & Bogousslavsky, 2002), and while it is most commonly reported for hemiplegia, some cases have also been reported for unawareness of depression (Biran & Chatterjee, 2003). This has not been widely studied. High concordance has been found between patient and family/staff ratings of mood (Gordon et al, 1991), suggesting that depression can be diagnosed in the absence of subjective report (Ramasubbu & Kennedy, 1994). As there is limited information of criteria for evaluating anosognosia for mood, it is desirable to measure a patient's self-report of mood against that of a significant other (Spencer et al, 1997). This is a further advantage of including an observer-rating of mood in the present study as it did not just rely on patient reports.

5.3.3 Sample size and recruitment

At the start of the study recruitment took place in two hospitals in Nottingham (Queens Medical Centre and Nottingham City Hospital). However, due to the low rate of recruitment initially, ethical approval was obtained to recruit from two additional local hospitals (Mansfield Community Hospital and Derbyshire Royal

Infirmary). The low rate of recruitment was primarily due to patients declining to participate, rather than patients not meeting the study criteria. There may therefore be bias due to self-selection. Non-participation in epidemiological research has the potential to introduce bias (Jacomb, Jorm, Korten, Christensen, & Henderson, 2002). There are several possible reasons why the recruitment rate was low. In accordance with ethical guidelines, patients were only included if they gave informed consent or assent was obtained from a relative. Anecdotally, some patients made comments such as 'not having enough time', 'having too much else to do or worry about', 'couldn't be bothered' or simply 'not interested'. It is possible that one month after stroke is too early for some patients to decide to participate in a research project. Only one of the hospitals had a Clinical Psychologist based on the ward and so the role of a psychologist may have been unfamiliar and could have deterred patients from participating. Perhaps because the study was a survey rather than an intervention, some patients may have felt there was no benefit to taking part. Also, there were several research projects taking place on the stroke wards and some patients were invited to take part in more than one study and so they may not have wanted to participate in multiple studies.

It is possible is that patients with lower mood declined to participate, as characteristics of depression include a lack of interest and low motivation. Also, patients who were depressed may have been reluctant to disclose their mood to someone they didn't know. The sample could therefore be biased towards patients with less severe distress problems, but patients those who declined to take part could not be assessed for comparison. Thompson, Heller and Rody (1994) argued that older adults with depression or psychological distress are more likely to refuse

research invitations. This is an important issue as it may lead to an underestimation of distress. A recent audit concerning cognitive impairments and emotional distress by the Clinical Psychologist on the stroke ward at Queens Medical Centre (Macniven, McKeown, Chambers, & Lincoln, 2005) found similar recruitment problems to this study. Many patients refused to do the assessments and many of those that did were thought by ward staff to have low mood. Macniven et al (2005) however found higher levels of distress than this study although the sample size was small (n=19) and time after stroke was not specified.

One hundred patients were assessed at baseline and the attrition rate was low with a majority of patients reassessed at six months. This may be because the researcher made every effort to contact and reassess the patient face to face rather than postally. There was also very little missing data on questionnaires, this is likely to be because the researcher completed the assessments with the patient. However, the sample size was smaller than some of the studies in the literature such as Burvill et al (1995) (n=294), House et al (1991) (n=128) and Wade et al (1987) (n=379). These studies recruited patients from community stroke registers and/or G.Ps and so were recruiting from a larger population. Also, these studies recruited patients over a longer period of time. The time span of the present study restricted the sample size that could be obtained. Also, when patients are in hospital it can be difficult to find a convenient time and a quiet room in which to assess the patient. The sample size limited the complexity of the model that could be analysed. Further studies to assess the constructs of the model in more detail should use a larger sample in order for more detailed relationships and interactions to be evaluated and to replicate the findings of the present study.

Patients were recruited from hospital, therefore the sample was biased towards those with more severe or disabling strokes and the findings may not necessarily apply to patients with milder strokes not admitted to hospital. The reasons for this approach were discussed in the methodology of Chapter 4. However, the method of identifying patients in hospital enabled the study of the role of psychosocial constructs such as locus of control, coping and social support in patients whose stroke has been disabling enough for them to be hospitalised. Identifying patients in hospital enabled patients to be approached by about two weeks post-stroke to be first assessed and a majority of stroke patients are admitted to hospital.

5.3.4 Timing of assessments

Patients were reassessed at six months after stroke. All patients had been discharged by this point. Most spontaneous recovery is expected by three months with little further recovery after six months (Ebrahim & Harwood, 1999). This suggests that the follow up assessment at six months was an appropriate time to assess patients when recovery had plateaued and they were living with the consequences of stroke. This is informative as many patients are still receiving rehabilitation in the first six months (in hospital or through the community stroke team) and intervention strategies could be implemented within this. It was also identified in the literature review that distress early after stroke has a negative impact on rehabilitation. It was therefore important to identify predictors of emotional distress in the first six months after stroke. The time constraints of the PhD precluded a longer follow-up assessment, although justification for the timing of assessments was outlined in the Method chapter. It does however mean that the findings from the present study can only be applied to the first six months after stroke. Different factors may be related to distress later after

stroke, perhaps depending on the impact the stroke has had on everyday life. Ideally a study would assess a large sample of patients within the first month after stroke and systematically follow them up in the years following the stroke. This would be difficult in practice as it requires a large amount of funding and would be and time consuming. Also, if assessing patients in the later years after stroke it is difficulty to surmise whether the distress was due to the stroke or other factors.

5.3.5 Aphasia

Aphasia is not often objectively assessed in studies of emotional distress after stroke (Spencer et al, 1997). Language impairment was assessed using the Sheffield Screening Test (SST) and justification for this was detailed in the Method chapter. It is important to note that scoring below the age-related cut-off on the SST was not equivalent to a clinical diagnosis of aphasia. The SST did not provide sufficient detail about the language impairment to explore whether particular characteristics of aphasia were related to distress. This would require a more detailed assessment. It would be interesting to see whether the impact of aphasia on everyday activities was related to distress, as aphasia affects many areas of everyday life (Code et al 1999; Code 2003). For example, the recently published Comprehensive Aphasia Test (Swinburn, Porter, & Howard, 2004) has a detailed battery assessing multiple areas of language (comprehension, spoken language, reading and writing). This assessment was published after completion of the present study but may be suitable for future studies to investigate in detail the relationship between aphasia and distress.

Visual analogue scales (VAMS and VASES) were included as measures of distress Patients with aphasia were able to complete the scales, this may be because the researcher completed the assessments with the patient. Price, Curless and Rodgers

(1999) argued that many stroke patients are unable to complete visual analogue scales. However, this conclusion was based upon patients rating the degree of tightness of a sphygmomanometer cuff on five different visual scales which did not include pictures. The visual analogue scales used in the present study were developed for patients with communication problems and have been validated in stroke, but are obviously limited in the depth of information they provide about patients' mood.

5.3.6 Statistical techniques

Parametric statistical tests were employed to test for differences between groups on assessments (using t-tests) and for evaluating correlations between variables (Pearson's correlations). Multiple linear regression was used to explore predictive relationships between variables and emotional distress. Parametric analyses make assumptions, in particular that data is measured on an interval or ratio scale and that data is normally distributed. Justification for the use of parametric statistics were detailed at the outset of the Results chapter. A liberal interpretation of the interval level data assumptions was taken as a strict conservative interpretation would mean that very little data in psychological research would be defined as continuous (Miles & Shelvin, 2001). Parametric tests allowed a more detailed examination of the relationships between constructs through linear regression and mediation analyses. There is disagreement in the literature as to whether parametric tests can be performed on ordinal data, therefore those who take a more conservative view may criticise the use of parametric tests in this study.

Parametric tests assume data is normally distributed, however it is rare to find a naturally occurring normal distribution (Dunlap et al, 1995). Data on the main outcome measures of distress used in the present study were slightly skewed but

were not significantly different from the normal distribution. A degree of skew is not surprising as it is expected that few patients score at the extreme of the scale. It is possible that Pearson's correlation underestimated the strength of correlation between variables as correcting skew has been found to increase the magnitude of correlation between variables (Dunlap et al, 1995). The HADS distress score was also found to be positively skewed in stroke patients by Townend (2004) who also did not transform the data, arguing that there is a theoretical basis for the data being skewed. Dichotomising the outcome measure would have resulted in a loss of detail and the present study was concerned with emotional distress rather than a discrete emotional disorder. Transforming the data would also make interpretation of findings more difficult. Further, Pearson's correlation (Norris & Aroian, 2004) and t-tests (Nanna & Sawilowsky, 1998; Sawilowsky & Blair, 1992) have been found to be relatively robust to Type I error.

Data was collected on several assessments and many pairwise comparisons and correlations were performed. These comparisons were performed with a theoretical basis rather than performing every possible comparison between all variables. Carrying out multiple comparisons increases the probability of a Type I error (falsely rejecting a null hypothesis). In order to account for this a Bonferroni correction could have been performed whereby the significance level is adjusted to be more stringent to account for the number of comparisons (0.05 divided by the number of comparisons performed). If the Bonferroni correction had been employed in this study then some of the correlations would have no longer been significant. The limitation of this correction is that it is conservative if many comparisons are performed and so it increases the chance of a Type II error (failing to reject a false

null hypothesis). Previous stroke research has also not corrected significance but has acknowledged this limitation (Blake, 2001). Also, the tests of mediation may have low power due to the sample size study. Interpretation of the results should acknowledge the number of statistical tests performed, however each of the tests conducted had a theoretical basis.

Multiple linear regression was conducted as it was considered appropriate to identify predictors of emotional distress, both cross-sectionally and across baseline and follow up assessments. Logistic regression was employed in the secondary analysis in Chapter 3 as the outcome variable was dichotomous. Other studies have also used multiple linear regression to explore factors related to distress after stroke (Dennis et al, 2000; Hosking et al, 2000; Berg et al, 2003). To further explore the direction of causality between factors over time a cross-lagged panel correlation analysis could have been conducted. For example, to explore the relationship between RLOC and distress, the correlation between RLOC and distress at baseline would be compared to the correlation between distress at baseline and RLOC at follow up. The strongest correlation would indicate the most likely direction of causality. To use this technique to test mediation with one intervening variable would require a minimum of k+2 time points, where k is the number of intervening variables (Farrell, 1994). Therefore, to test mediation using cross-lagged panel correlations would have required a minimum of three time points of assessment. This approach has also been criticised for being too simplistic as it cannot be easily applied when there are more than two variables and it does not take into account the influence of a variable on itself (autoregression) (Farrell, 1994). An alternative analysis would have been structural equation modelling (SEM). SEM is a complex technique in which the

researcher formulates a hypothesis about the underlying model and the hypothesis is then tested, although if the model does not fit the data then the parameters estimates are not meaningful (Miles & Shelvin, 2001). The advantages of SEM are that it controls for measurement error, it provides detail on the fit of the entire model, and it allows multiple predictors, outcome variables and mediators (Frazier et al, 2004). This would have allowed detailed evaluation of the direction of causality between factors using longitudinal data. However, SEM is a complex approach that requires a sufficiently large sample size, suggested at ten subjects per parameter (not per variable) (Frazier et al, 2004) and such a large sample is difficult to obtain with patient populations. Even with SEM there can be equivalent models consistent with the data. Therefore, multiple regression was suitable in view of the sample size and the fact that all of the constructs assessed in this model have not been previously considered simultaneously. If future studies aim to study the inter-relationships between the constructs identified in the present study and a sufficiently large sample were obtained then it may be appropriate to perform SEM.

5.3.7 Factors not included in the study

The regression models although significant did not account for all of the variance in distress at baseline and follow up. The present study did not measure every construct that may have some relationship with distress. Stroke patients are limited in the number and nature of assessments that it is reasonable to ask them to complete. Moreover, the assessments that were included were selected to measure the constructs in a theoretical framework. Therefore the framework included constructs that were considered relevant from the literature rather than including a multitude of assessments in order to 'fish' for trends in the data. This section will briefly consider factors that were not considered in the present study.

Mercier et al (2001) found that motor, cognitive and perceptual factors contributed to the ability to perform activities of daily living (ADL). As ADL were related to distress in the present study it is possible that these factors may be related to distress if they impact upon everyday behaviours. Cognitive impairment such as memory, global cognitive function and perceptual problems were not assessed. Some researchers have reported a significant negative correlation between scores on the Mini Mental Status Examination (MMSE) and depression (Robinson et al, 1986; House et al, 1990). Others found no significant relationship (Pohjasvaara et al, 1998; Burvill et al, 1997; Ng et al, 1995; Eastwood et al, 1989). Information regarding patient's cognitive functioning in this study sample would have provided an additional descriptor of patients' impairments. However, to include a detailed battery of neuropsychological assessments was beyond the aims of the present study, as it was concerned with assessing psychosocial variables that may relate to distress.

There is some evidence to suggest that stressful life events are related to depression in the general population (see Kessler, 1997 for a review), and there has been some consideration of this in stroke. Bush (1999) found that at six months after stroke, patients were at a greater risk of developing depression if they reported a major life event *since* their stroke, but no relationship at three months or one year. However, the authors did not report what the life events were or any stroke characteristics. Life events were not recorded in the present study as there was not sufficient evidence in stroke patients to support this as being an important factor and they cannot be changed. Also, it may be problematic to obtain accurate retrospective reports of events. Personality traits have also been studied. Aben et al (2002) found high

neuroticism scores at one month post-stroke were related to depression at one year. It is possible that this could be a reflection of anxiety levels. Also, there is evidence that personality changes can occur following stroke (Haga, Dennis, Wardlaw, & Sharpe, 2004; Stone et al, 2004). However, the personality changes were rated by a carer rather than assessing self-reported personality traits, and many of the characteristics could be a reflection of depression, such as unhappy, irritable, withdrawn and energetic. To assess post-stroke personality adequately may have required a lengthy assessment. Also, personality traits would not be amenable to intervention.

Activity level measured using the Nottingham Extended Activities of Daily Living (EADL) scale was related to distress. To explore activity level further it would have been informative to assess leisure activity. The EADL has a leisure subscale consisting of six items, but this does not cover in detail hobbies or other activities. Also, it cannot be assumed that just because people carry out activities such as cooking and gardening that they enjoy these. There is evidence that leisure activities decrease after stroke (Sjögren, 1982; Drummond, 1990), but the relationship between leisure and distress in stroke patients requires further research.

5.4 Strengths of the study

This design and methods used in this study were developed to address limitations and gaps in identified in the literature concerning distress after stroke. A longitudinal design was employed in order to assess patients in hospital during the acute stage post-stroke and follow them up during later stages of recovery (six months). This provided information on the natural history of emotional distress in the first six months after stroke. The prospective assessment of patients in hospital and after

discharge enabled examination of which factors assessed early after stroke predicted subsequent distress. Large community studies have been longitudinal (Burvill et al, 1995; House et al, 1991; Wade et al, 1987), although Burvill et al (1995) only reassessed at one year those patients who were depressed at four months. However, only a few studies which recruited patients from in hospital have systematically followed them up (Astrom et al, 1993; Berg et al, 2003; Knapp & Hewison, 1998; Parikh et al, 1990). In contrast to the present study, other studies have only assessed patients in the first month after stroke or have not assessed patients until six months or one year post-stroke.

Broad but precise inclusion criteria were used. This was in order to obtain a sample representative of the range of stroke patients. Inconsistent inclusion and exclusion criteria have been used in the literature making comparisons of studies difficult. The present study included patients who had had more than one stroke, but also recorded pre-stroke disability. Some studies have excluded patients who have had a previous stroke, however, this leaves a sample less representative of the stroke population, as the recurrence rate of stroke is about 5% per year (Warlow, 1998). Similarly, some studies have excluded patients with a history of depression. The present study included patients with a history of depression documented in hospital medical notes The limitations of this method were considered previously in this discussion. Information that was also collected in this study was an assessment of the patient's pre-stroke levels of personal and extended ADL. However, the accuracy of patient's ability to recall what their activity level was before their stroke has not been verified. Information about pre-stroke extended ADL is not usually reported.

One of the most important strengths of the present study was the inclusion of patients with aphasia. It also emerged that language problems were one of the major determinants of distress which supports this approach. Visual analogue scales and an observer rating of mood enabled some information about the mood of aphasic patients to be reported and to examine factors related to this. Also, the sample was therefore more representative of the disabilities experienced by stroke survivors. It also demonstrated that the methods used were appropriate for those with communication problems. Furthermore, the Sheffield Screening Test was used to provide a brief description of receptive and expressive language, and the degree of language impairment. This provided objective criteria to decide whether patients completed some or all of the assessment battery unlike most other studies which did not document criteria by which patients were considered to have 'aphasia'.

Multiple sources of information be should collected to assess depression in stroke (Gordon & Hibbard, 1997), particularly for patients unable to complete a self-report measure of mood. Consequently, this study included an observer measure of mood developed for stroke, and this correlated with self reported mood. This method was considered advantageous in comparison to relying solely on either self- or observer-reports.

5.5 Clinical implications and recommendations for future research

The National Clinical Guidelines for Stroke (RCP, 2004) recommend that patients are screened for anxiety and depression within the first month of stroke and their mood reviewed. The findings in the present study support this, particularly as distress remained persistent at six months post-stroke. Furthermore, emotional distress may be more common than reported in this thesis as patients with low mood may have

declined to participate. Despite the clinical guidelines there is only a 50% compliance rate of hospitals with inpatient screening and a median of 54% review mood after discharge (Bowen, Knapp, Hoffman, & Lowe, 2005).

The National Clinical Guidelines do not provide specific recommendations regarding the mood assessments that should be used with stroke patients, particularly patients with communication problems. This may influence the low compliance rate with clinical guidelines. The assessments used with all patients in the present study were the VASES-D, VAMS-HE SADQ-H and these were found to be suitable for aphasic patients. The internal consistency for the VASES-D was higher than the VAMS and so the VASES-D may recommended as a screening measure appropriate for aphasic patients. However, a clinical interview would be required to provide a diagnosis of depression, although there is no gold standard diagnostic tool for people with aphasia. The SADQ-H was used as an observer rating of mood. It was correlated with the HADS depression and total scores and had high internal consistency which provides further support for its use as a measure of mood in stroke patients. The SADQ-H may therefore be suitable as a screening measure and can be completed by staff in hospital to aid the identification of patients who require a more detailed assessment. The HADS was suitable as an assessment of distress in patients without communication problems and had high internal consistency which concords with previous validation studies in stroke (O'Rourke et al, 1998).

Emotional distress was remained common at six months post-stroke thus mood monitoring and intervention efforts should not just be focused during the acute stages post-stroke but also after discharge. The National Clinical Guidelines for Stroke

state that mood should be kept under review but do not specify how mood should be monitored after patients have been discharged from hospital. Distress at baseline was found to be a significant predictor of distress at follow up in the whole sample, therefore it is recommended that early interventions should be evaluated to examine whether this prevents later distress.

A recent Cochrane Review of interventions for depression after stroke found some evidence for a reduction in scores on depression rating scales, but no strong evidence of benefit for pharmacotherapy or psychotherapy on the remission of depression (Hackett, Anderson, & House, 2004). Intervention studies have been limited by inadequate sample size, treatment for insufficient duration and short duration of follow up.

The National Clinical Guidelines for Stroke recommend that minor depression should be managed by 'watchful waiting' and more severe or persistent depression should be considered for antidepressants or psychological therapy. However, antidepressants should not be used to prevent depression. A review of non-drug strategies for psychosocial difficulties after stroke found mostly negative or weakly positive results, supporting the observation that single and simple interventions are not usually effective in rehabilitation, and therapists' work was often not based on explicit psychological theory (Knapp, Young, House, & Forster, 2000). Recommendations for therapeutic approaches in clinical practice need to be made in the context of the resources available. For example, 72% of stroke units do not have access to clinical psychology, and those that do receive a low level of input (Bowen et al, 2005).

The presence of negative cognitions and the decrement of positive cognitions was significantly related to distress and so supported the cognitive model of depression. The Stroke Cognitions Questionnaire Revised (SCQR) could be used to assess whether patients report depression related cognitions which could be addressed with psychological therapy. Future research could address whether the SCQR is sensitive to changes in cognitions during cognitive behaviour therapy. Activity level was related to distress at baseline and at six months, supporting the behavioural model of depression, as lower activity level would be expected to be associated with less positive reinforcement. These two findings provide theoretical support for the use of cognitive behaviour therapy (CBT) to treat distress, as CBT aims to modify/restructure maladaptive thoughts and behaviours. CBT may be appropriate for patients reporting negative cognitions and who have low activity levels. Cognitive strategies address the persistent negative thinking, while behavioural strategies aim to maximise mood elevating activities. Single case experimental designs of CBT in stroke found that of the 19 patients four consistently showed benefit in mood, six showed some benefit and nine no benefit (Lincoln et al, 1997). This study was limited as it did not include a control group and did not follow up patients. A subsequent randomised controlled trial found no evidence for CBT being more effective than an attention placebo (Lincoln et al, 2003). The authors suggested that one reason for a non-significant finding was that the CBT was of low intensity and short duration (mean 9.85 therapy sessions), and also that depressed patients were identified through postal questionnaires. Further work is needed to examine the intensity and duration of therapy that is required. As CBT aims to decrease negative thinking and increase activity level, trials of CBT should monitor activity levels and

cognitions to examine whether these are changed by therapy. Also, content analysis of treatment would be useful to identify what the components of therapy are and whether these are related to whether the intervention is effective.

Therapies such as CBT may need to be modified for patients who have cognitive deficits or communication problems. For example, Khan-Bourne and Brown (2003) suggested adaptations such as using memory aids, shortened sessions of greater frequency and involving a family member to assist between sessions. Also, when cognitive deficits limit the patient's ability to understand cognitive distortions, there should be a proportionally greater emphasis placed on behavioural interventions (Hibbard, Grober, Gordon, Aletta, & Fereman, 1990). These modifications should be documented by researchers, in addition to using a manualised treatment, to allow replication of the therapy.

Locus of control was related to distress and this may be amenable to intervention. However, Frank et al (2000) aimed to modify control beliefs in stroke patients using a workbook based intervention but this was not effective. Coping strategies were indirectly related to emotional distress by affecting locus of control in patients without communication problems. This suggests that rather than trying to manipulate locus of control directly, this should be done by altering coping strategies (increasing adaptive coping and decreasing maladaptive coping). No study has investigated an intervention that specifically aims to train stroke patients to develop more adaptive coping strategies. Kennedy, Duff, Evans and Beedie (2003) developed coping effectiveness training which in addition to cognitive behavioural skills teaches appraisal skills to guide the choice of coping strategies. This has been implemented

in group form in spinal cord injury patients and significantly reduced BDI scores post-treatment (Kennedy et al, 2003). However, the follow up assessment was only six weeks after the intervention so the sustainability of this therapy is unknown and there was no corresponding change in coping strategies. It is not known whether this therapy could be applied to all stroke patients, in particular those with communication problems or severe cognitive impairment. To evaluate whether coping effectiveness training is an effective treatment in stroke patients, a randomised controlled trial could be conducted in those patients who report a preponderance of maladaptive coping strategies and little adaptive coping. The trial should compare the intervention with an attention placebo and a waiting list control. An attention placebo group should be included to determine whether any improvement is attributable to the content of the intervention or non specific support provided by the group. Patients should be reassessed at the end of the intervention and at a longer follow up than Kennedy et al (2003), for example six months to evaluate whether any effect of the intervention is sustained.

RLOC scores were significant in the regression models predicting distress at baseline and at follow up and RLOC was a mediator of the relationship between coping and distress at both baseline and follow up. However, RLOC scores at baseline were not a significant predictor of distress at follow up. The possibility that RLOC scores at follow up were caused by distress at the initial assessment cannot be excluded. The possibility that this also applies to communication impairment and activity level cannot be dismissed, namely that distress may worsen communication impairment and activity level, perhaps through distressed patients being less motivated to participate in rehabilitation. The direction of causality could be tested in future

studies using experimental manipulation. For example, an intervention study designed to manipulate a proposed predictor variable, such as locus of control, communication impairment or activity level would be conducted. The proposed predictor variable and distress would be assessed at multiple time points (before and after the intervention) to evaluate whether a change in the manipulated variable is associated with a corresponding decrease in distress.

Patients who were classified as aphasic had higher levels of distress than non aphasic patients and the severity of communication impairment was related to distress. This suggests that an intervention to improve communication may improve mood. A study which examined the psychological effects of speech therapy found no significant difference between mood ratings of patients (using simple rating scales) who did or did not receive speech therapy over 24 weeks, and mood was unrelated to recovery (Lincoln, Jones, & Mulley, 1985). However, there was also no significant improvement in communication which may account for the negative findings. If a significant effect was found, it would be difficult to determine whether this was due to the speech therapy or the counselling/support role of the therapist. In order to test this, a randomised controlled trial would be needed that included an attention placebo, to examine which components of therapy were relevant. The finding that communication impairment was related to distress highlights that psychological interventions suitable for patients with communication problems should be evaluated.

Activity level was also related to distress in aphasic patients. This suggests that an intervention which increases activity level may decrease distress. Behaviour therapy

may be an appropriate intervention to treat distress in aphasic patients as behavioural techniques are concrete and practical and can be adapted for people with communication problems, for example, encouraging the use of intact communication skills and using visual aids. Behavioural techniques aimed at increasing activity levels include activity monitoring, activity scheduling and graded task assignments. There is evidence that behaviour therapy is effective at treating distress in the general population (Jacobson et al, 1996; Robinson, Berman, & Neimeyer, 1990), the elderly (Thompson, Gallagher, & Steinmetz, 1987), and people with Alzheimer's disease (Teri, Logsdon, Uomoto, & McCurry, 1997), but this has not been evaluated in stroke. The author of this thesis and colleagues from Nottingham are currently conducting a randomised controlled trial of behaviour therapy to treat distress in aphasic stroke patients.

The amount of practical support received was related to distress at six months post-stroke, as patients who reported receiving less practical support were more distressed. This indicates that a social support intervention may be appropriate in the later stages post-stroke. Friedland and McColl (1992) however found that a social support intervention programme involving improving existing supports and establishing new supports did not improve mood. However, patients were about one year post-stroke, therefore the intervention may have been too late. It may be more appropriate to offer interventions when patients are in hospital and are preparing for discharge. Studies of family support organisers (FSO) who provide services such as information on adapting to disability and benefit entitlements found the FSO service did not significantly improve mood (Lincoln, Francis, Lilley, Sharma, & Summerfield, 2003). Lincoln, Francis, Lilley et al (2003) recommended that rather

than offering a blanket service to all patients and carers, patients should be referred to the FSO when they require specific help. A support service such as the FSO may be suitable as a targeted intervention for patients who require help with a specific area, such as adapting to their disability. To test this a pragmatic trial would be required in which patients and their carers are informed about the FSO service and are referred to the FSO to address a specific need, compared to a waiting list control to evaluate whether the intervention reduces distress.

5.6 Summary and Conclusions

This thesis consisted of three empirical studies which were designed to explore factors relating to emotional distress after stroke. The theoretical framework developed from the literature review was used to guide the programme of research. This research is an important contribution as previous work has been mostly atheoretical and has overlooked the role of psychosocial factors. This section will summarise the main findings from the studies presented in Chapter 2, Chapter 3 and Chapter 4, and the implications of these will be considered.

Chapter 2 reported the development and validation of the Stroke Cognitions Questionnaire Revised (SCQR). Evidence for the efficacy of CBT to treat emotional distress after stroke has been mixed, raising the question of whether the cognitive model of depression was not applicable to stroke patients. However, previous studies which investigated the cognitions of stroke patients used measures developed for psychiatric samples and which may have had low content validity. The Stroke Cognitions Questionnaire (Nicholl et al, 2002), an assessment of the frequency of positive and negative cognitions developed using CBT treatment notes from stroke patients, was revised in response to the findings of Nicholl et al (2002) and evaluated in a sample of 50 hospitalised stroke patients. The SCQR was found to have good internal consistency, inter-rater reliability and test-retest reliability. The scale had a two-factor structure corresponding to positive and negative cognitions. Patients classified as depressed using the BDI-II reported significantly more negative cognitions and significantly less positive cognitions than those who were not depressed. This finding support the cognitive model of depression and suggests that CBT is appropriate for stroke patients. The SCQR may provide a useful tool for

screening stroke patients to identify those who may benefit from CBT. It is also a potentially useful tool for monitoring the effectiveness of CBT, but evaluation of the sensitivity of the scale to detect change during treatment is required before it can be recommended for this purpose.

Chapter 3 presented secondary analysis of data from a randomised controlled trial of CBT to treat depression after stroke (Lincoln & Flannaghan, 2003). Data were used to explore factors relating to depression. Communication impairment at recruitment was a significant predictor of depression severity at recruitment to the study and when patients were reassessed at follow up (six months later), although patients with severe communication impairment were excluded from the study. Depression severity at recruitment was a significant predictor of depression severity when patients were reassessed at follow up (six months later). Communication impairment, depression severity and recovery locus of control at baseline were significant predictors of depression at follow up. The logistic regression models had low sensitivity and the R^2 for the models were low, suggesting that other factors should be assessed. The sample was limited as patients were part of a treatment trial, it did not include patients with severe communication impairment and other psychological factors such as coping and social support were not assessed. The findings and limitations were used to inform the design of the main study for the thesis.

The main study of the research programme is presented in Chapter 4 and was a longitudinal study evaluating the components of the theoretical framework for the study of emotional distress after stroke. The study found that the factors associated with distress early after stroke (one month) and late after stroke (six months) were

similar. This suggests that distress early and late after stroke is not aetiologically different and that interventions early after stroke should be evaluated to examine whether they prevent distress after stroke.

The main factors found to be associated with distress were increased communication impairment, lower activity level, a more external locus of control (with the relationship between coping and distress mediated by locus of control) and suffering an anterior circulation stroke (TACS or PACS). These finding have important implications because all of these factors except anterior circulation stroke are amenable to psychological intervention. The psychological factors were proposed in the theoretical framework outlined in this thesis to be associated with distress after stroke; therefore the theoretical framework was supported. The findings also supported the behavioural theory of depression, as communication impairment and lower activity level are likely to result in reduced participation in everyday activities and interactions with others. Consequently, this would lead to reduced positive reinforcement due to reduced opportunities for reinforcement in the environment and reduced activity level which in turn leads to distress (Lewinsohn et al, 1985). Support was also found for the cognitive model of depression as patients who had higher levels of distress reported more negative cognitions and less positive cognitions than those who were less distressed and the cognitions measure was relevant to stroke. Locus of control and to an extent coping strategies were related to distress which provides evidence for the proposal that coping is a mediator of emotional response (Lazarus & Folkman, 1984; Folkman & Lazarus, 1988), therefore the way an individual reacts to and copes with the stroke also influences distress.

An important issue when investigating factors relating to emotional distress is the direction of causality between the factor, such as locus of control, and distress. As discussed previously (see pages 172 and 248), it is possible that there is feedback whereby distress has a negative influence on locus of control. However, in Chapter 3 recovery locus of control at baseline remained a significant predictor of depression at follow up when baseline depression scores were included in the logistic regression. In contrast, in Chapter 4 recovery locus of control at baseline was not a significant predictor of distress at follow up. Possible reasons for this discrepancy have been considered (see page 312). To explore the direction of causality in detail would require more sophisticated analysis using techniques such as cross-lagged panel correlations or structural equation modelling. These approaches were not appropriate in Chapters 3 and 4 as ideally data would be collected on at least three occasions from a much larger sample. The direction of causality could also be investigated using experimental manipulation. For example, an intervention study could be conducted to manipulate a risk factor for distress, such as using a behaviour therapy to improve activity level, and it could be assessed whether an increase in activity level is associated with a corresponding decrease in distress.

In conclusion, the programme of research reported in this thesis has demonstrated the importance of psychological factors in emotional distress after stroke. This thesis has superseded previous research which has only considered one or two psychological factors in isolation and has not been based on a theoretical rationale. The findings from this thesis were used to make recommendations for evaluations of psychological interventions to treat or prevent distress after stroke. In particular, the results across the three studies indicate that cognitive behavioural interventions may

be appropriate as factors such as locus of control, coping and cognitions were found to be relevant. However, for patients with severe communication impairment or cognitive problems CBT may be difficult to conduct. For these patients it is recommended that the behavioural components of CBT may provide a useful therapeutic tool as these approaches are concrete and practical, and there is guidance on adapting CBT for such patients (Grober et al, 2003; Khan-Bourne & Brown, 2003). Future research should evaluate the proposed interventions suggested in this chapter as the findings could inform future clinical guidelines and would provide further validation of the findings of this thesis.

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APPENDIX I

STROKE COGNITIONS QUESTIONNAIRE REVISED (SCQR)

Stroke Cognitions Questionnaire Revised

Below are listed some statements that stroke patients have made. Please indicate how often you have had each thought in the past month by circling the appropriate category. Some of them may not apply to your situation. If this is the case and you have never had the thought then simply circle the word 'Never.' Some of them are very negative. Not all people experience such negative thoughts, but we would like to know whether you have.

1) 'I have lots to look forward to'

Often Sometimes Rarely Never

2) 'I still get a sense of satisfaction and achievement from life'

Often Sometimes Rarely Never

3) 'I feel inadequate and helpless'

Often Sometimes Rarely Never

4) 'I still have motivation and interest in things I used to enjoy'

Often Sometimes Rarely Never

5) 'I get irritated easily'

Often Sometimes Rarely Never

6) 'I feel a burden to others'

Often Sometimes Rarely Never

7) 'I'm optimistic about the future'

Often Sometimes Rarely Never

8) 'I'm frustrated about not being able to do the things I want to'

Often Sometimes Rarely Never

9) 'I wonder what the point of living like this is'

Often Sometimes Rarely Never

10) 'I'm accepting my limitations and disabilities'

Often Sometimes Rarely Never

11) 'There's no point in doing things if I can't do them as well as before'

Often Sometimes Rarely Never

12) 'I'm no good at anything'

Often Sometimes Rarely Never

13) 'I feel I'm in control of my life'

Often Sometimes Rarely Never

14) 'I feel alone and unwanted'

Often Sometimes Rarely Never

15) 'I feel like a failure'

Often Sometimes Rarely Never

16) 'I feel I have a lot left to give'

Often Sometimes Rarely Never

17) 'I have lost confidence in myself'

Often Sometimes Rarely Never

18) 'I dwell on what I'm unable to achieve'

Often Sometimes Rarely Never

19) 'There's lots to be happy about'

Often Sometimes Rarely Never

20) 'I can't be bothered to do anything'

Often Sometimes Rarely Never

21) 'I feel I am coping'

Often Sometimes Rarely Never

APPENDIX II

COPIES OF ASSESSMENTS

Due to copyright restriction the BDI-II cannot be reproduced and so is not included in the Appendix.

Sheffield Screening Test for Acquired Language Disorders

Diana Syder, Richard Body, Mark Parker, Margaret Boddy

Score Sheet

Client's Name..... Date of birth .....
Tester's Name..... Date of test.....

Full instructions for administration and scoring are contained in the Manual

Receptive Skills (Section 2)

1. **Verbal Comprehension of Single Words** Score

I'm going to ask you to point to some of the things in the room.
door_____ light ____ chair ____ ceiling ____ corner ____ ☐

2. **Comprehension of Sequential Command**

a) Point to the window and then the door ☐
b) Before pointing to the ceiling, touch the chair ☐

3. **Comprehension of a Complex Command**

Tap the chair twice with a clenched fist, whilst looking at the ceiling ☐

4. **Recognition of Differences in Meaning Between Words**

I'm going to read you a list of words and I want you to tell me which is the odd one out:

a) chicken, duck, apple, turkey ☐
b) run, drink, walk, sprint ☐
c) small, large, massive, huge ☐

5. **Comprehension of a Narrative**

a) I'm going to read you a short paragraph and then ask you a question about it.

John went to the shop to buy a pen. When he got there he found that he had forgotten his wallet, so he came home and made himself a cup of tea.

What should he have taken with him? ☐

b) I'm going to read you another paragraph

Mrs Smith visited several shops. She bought a newspaper, a cauliflower a stamp and some sausages.

What was the second shop she visited? ☐

Receptive Skills: Total Score ☐

Sheffield Screening Test for Acquired Language Disorder

Expressive Skills (Section 3)

6. **Word Finding**
Tell me the names of three well-known places in *the client's home town.*

Score ☐

Score one mark if three names are given correctly

7. **Abstract Word Finding**
Tell me another word that means the same as:

a) beautiful; ☐
b) angry; ☐
c) ridiculous. ☐

8. **Sequencing**
Describe how you would make a cup of tea. ☐

A correct answer contains two or more appropriate stages in the right order

9. **Definitions**
Describe what the following words mean:

a) home; ☐
b) search; ☐
c) ambitious. ☐

10. **Verbal Reasoning**
I'd like you to tell me:

a) why you would use an umbrella; ☐
b) why people go on holiday; ☐
c) what would you do if you were locked out of the house. ☐

Expressive Skills: Total Score ☐

Receptive and Expressive Skills: Total Score ☐

Study Ref:_____ Date:_____ Centre:_____ Assessor:_____

BARTHEL INDEX

BOWELS	0 = Incontinent 1 = Occasional accident 2 = Continent	☐
BLADDER	0 = Incontinent/Catheterised 1 = Occasional accident (max 1 per day) 2 = Continent (for over 7 days)	☐
GROOMING	0 = Needs Help 1 = Independent (face/hair/teeth/shaving)	☐
TOILET USE	0 = Dependent 1 = Needs some help but can do something 2 = Independent	☐
FEEDING	0 = Unable 1 = Needs help cutting/spreading butter 2 = Independent	☐
TRANSFER	0 = Unable 1 = Major help (1-2 people, physical) 2 = Minor help (verbal or physical) 3 = Independent	☐
MOBILITY	0 = Immobile 1 = Wheelchair independent, incl corners 2 = Walks with help of 1 person (verbal/physical) 3 = Independent (may use aid, eg stick)	☐
DRESSING	0 = Dependent 1 = Needs help, but can do about half unaided 2 = Independent	☐
STAIRS	0 = Unable 1 = Needs help (verbal or physical, carrying aid) 2 = Independent up and down	☐
BATHING	0 = Dependent 1 = Independent	☐

TOTAL ☐

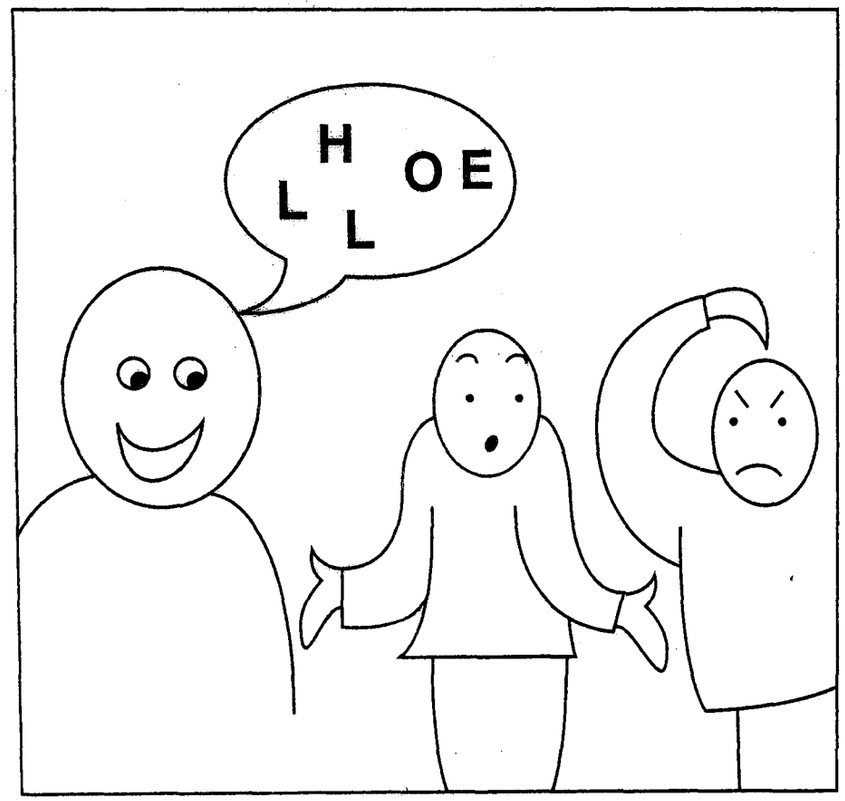
EXTENDED ACTIVITIES OF DAILY LIVING

The following questions are about everyday activities. Please answer by ticking ONE box for each question. Please record what you have ACTUALLY done in the last week.

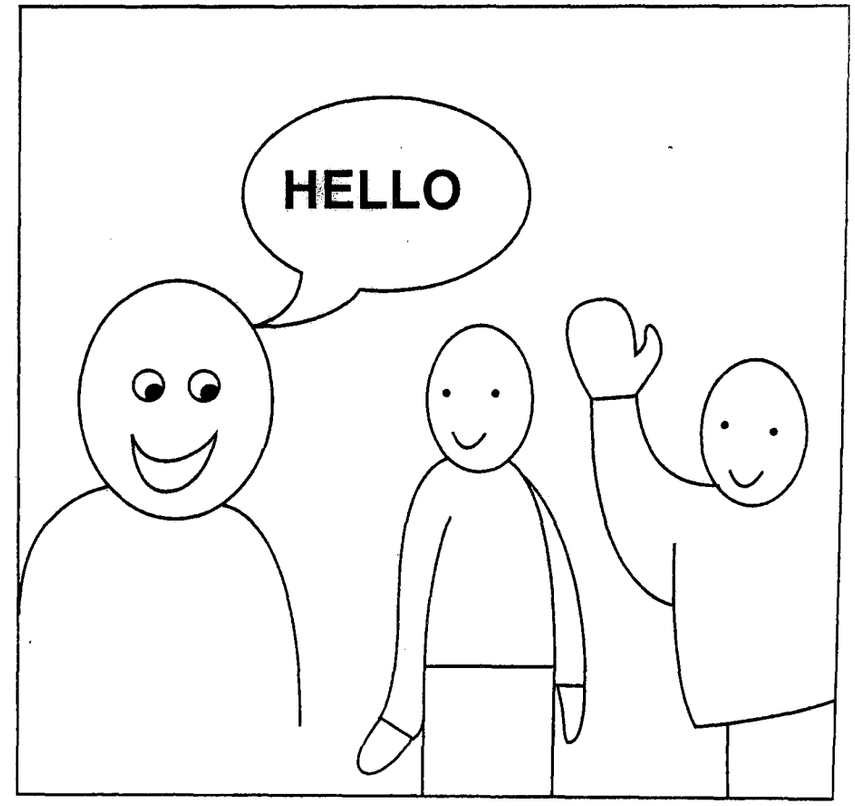
DID YOU.....	Not at all	with help	on your own with difficulty	on your own
1. Walk around outside?	☐	☐	☐	☐
2. Climb stairs?	☐	☐	☐	☐
3. Get in and out of a car?	☐	☐	☐	☐
4. Walk over uneven ground?	☐	☐	☐	☐
5. Cross roads?	☐	☐	☐	☐
6. Travel on public transport?	☐	☐	☐	☐
7. Manage to feed yourself?	☐	☐	☐	☐
8. Manage to make yourself a hot drink?	☐	☐	☐	☐
9. Take hot drinks from one room to another?	☐	☐	☐	☐
10. Do the washing up?	☐	☐	☐	☐
11. Make yourself a hot snack?	☐	☐	☐	☐

	No	With help	On your own with difficulty	On your own
12.Manage your own money when you were out?	☐	☐	☐	☐
13. Wash small items of clothing?	☐	☐	☐	☐
14.Do your own housework?	☐	☐	☐	☐
15.Do your own shopping?	☐	☐	☐	☐
16. Do a full clothes wash?	☐	☐	☐	☐
17.Read newspapers or books?	☐	☐	☐	☐
18.Use the telephone?	☐	☐	☐	☐
19. Write letters?	☐	☐	☐	☐
20.Go out socially?	☐	☐	☐	☐
21. Manage your own garden?	☐	☐	☐	☐
22. Drive a car?	☐	☐	☐	☐

not being understood



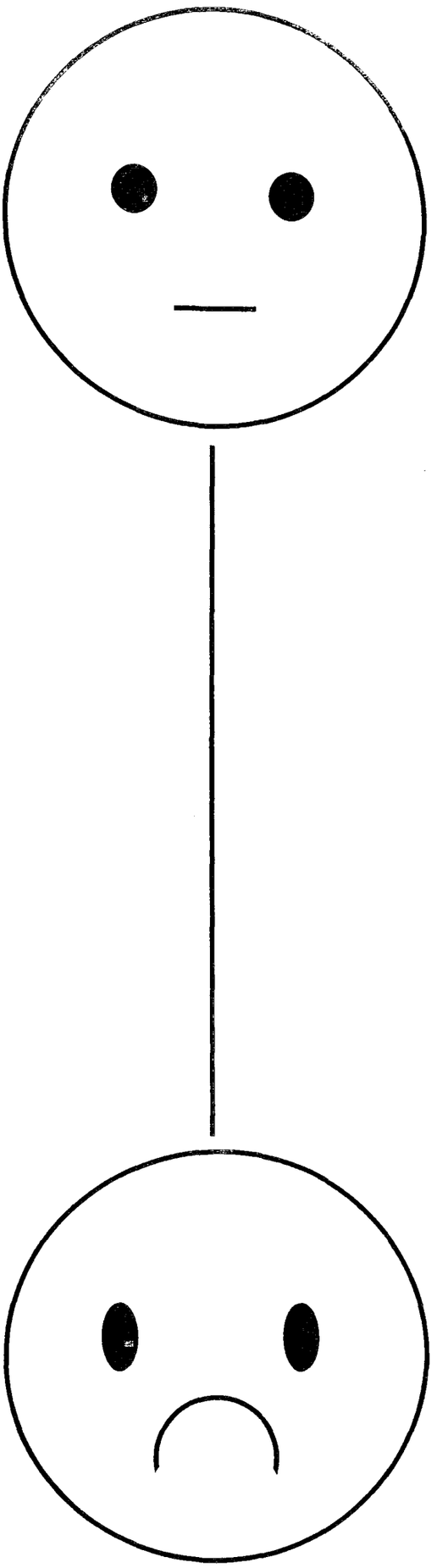
being understood



++ **+** **0** **+** **++**

Example VASES item

Neutral



Sad

THE STROKE APHASIC DEPRESSION QUESTIONNAIRE H (HOSPITAL VERSION)

Please indicate on how many days out of the last 7 the patient has shown the following behaviours:

1. Did his/her waking cause a disturbance in sleep patterns?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

2. Did he/she have weeping spells?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

3. Did he/she have restless disturbed nights?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

4. Did he/she initiate activities?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

5. Did he/she avoid eye contact when you spoke to him/her?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

6. Did he/she burst into tears?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

7. Did he/she smile when you spoke to him/her?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

8. Did he/she indicate suffering from aches and pains?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

9. Did he/she refuse to eat meals?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

10. Did he/she get angry?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

11. Did he/she refuse to participate in social activities?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

12. Did he/she laugh at a joke?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

13. Did he/she get restless and fidgety?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

14. Did he/she sit without doing anything?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

15. Did he/she concentrate on activities?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

16. Did he/she take care of his/her appearance to the extent of his/her physical ability?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

17. Did he/she seem to enjoy social acitivies or outings?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

18. Did he/she keep him/herself occupied during the day?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

19. Did he/she take sleeping tablets?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

20. Did he/she take interest in events around him/her?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

21. Did he/she look at you when you approached him/her?

Every day this week	On 4-6 days this week	On 1- 4 days this week	Not at all this week

Hospital Anxiety and Depression Scale

Please read each item and place tick in the box opposite the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or 'wound up':
- Most of the time .....
- A lot of the time .....
- Time to time, Occasionally .....
- Not at all .....

I still enjoy the things I used to enjoy:
- Definitely as much .....
- Not quite so much .....
- Only a little .....
- Hardly at all .....

I get a sort of frightened feeling as if something awful is about to happen:
- Very definitely and quite badly ...
- Yes, but not too badly .....
- A little, but it doesn't worry me ...
- Not at all .....

I can laugh and see the funny side of things:
- As much as I always could .....
- Not quite so much now .....
- Definitely not so much now .....
- Not at all .....

Worrying thoughts go through my mind:
- A great deal of the time .....
- A lot of the time .....
- From time to time but not too often
- Only occasionally .....

I feel cheerful:
- Not at all .....
- Not often .....
- Sometimes .....
- Most of the time .....

I can sit at ease and feel relaxed:
- Definitely .....
- Usually .....
- Not often .....
- Not at all .....

I feel as if I am slowed down:
- Nearly all the time .....
- Very often .....
- Sometimes .....
- Not at all .....

I get a sort of frightened feeling like 'butterflies' in the stomach:
- Not at all .....
- Occasionally .....
- Quite often .....
- Very often .....

I have lost interest in my appearance:
- Definitely .....
- I don't take as much care as I should
- I may not take quite as much care
- I take just as much care as ever .

I feel restless as if I have to be on the move:
- Very much indeed .....
- Quite a lot .....
- Not very much .....
- Not at all .....

I look forward with enjoyment to things:
- As much as I ever did .....
- Rather less than I used to .....
- Definitely less than I used to ...
- Hardly at all .....

I get sudden feelings of panic:
- Very often indeed .....
- Quite often .....
- Not very often .....
- Not at all .....

I can enjoy a good book or radio or TV programme:
- Often .....
- Sometimes .....
- Not often .....
- Very seldom .....

RECOVERY LOCUS OF CONTROL SCALE

Name: .....

Date: ..... **Record Number:** .....

These are statements other people have made about their recovery. Please will you indicate the extent to which you agree or disagree with them in the right-hand columns.

	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
1. How I manage in the future depends on me, not on what other people can do for me.					
2. It's often best just to wait and see what happens.					
3. It's what I do to help myself that's really going to make all the difference.					
4. My own efforts are not very important, my recovery really depends on others.					
5. It's up to me to make sure that I make the best recovery possible under the circumstances.					
6. My own contribution to my recovery doesn't amount to much.					
7. Getting better now is a matter of my own determination rather than anything else.					
8. I have little or no control over my progress from now on.					
9. It doesn't matter how much help you get, in the end it's your own efforts that count.					

Brief COPE

These items deal with ways you've been coping with stress in your life since you found out that you had had a stroke. There are many ways to try and deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not – just whether you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things	
2. I've been concentrating my efforts on doing something about the situation I'm in	
3. I've been saying to myself "this isn't real"	
4. I've been using alcohol or other drugs to make myself feel better	
5. I've been getting emotional support from others	
6. I've been giving up trying to deal with it	
7. I've been taking action to try and make the situation better	
8. I've been refusing to believe that it has happened	
9. I've been saying things to let my unpleasant feelings escape	
10. I've been getting help and advice from other people	
11. I've been using alcohol or drugs to help me get through it	
12. I've been trying to see it in a different light, to make it seem more positive	
13. I've been criticising myself	
14. I've been trying to come up with a strategy about what to do	
15. I've been getting comfort and understanding from someone	

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

16. I've been giving up the attempt to cope	
17. I've been looking for something good in what is happening	
18. I've been making jokes about it	
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping or shopping	
20. I've been accepting the reality of the fact that it has happened	
21. I've been expressing my negative feelings	
22. I've been trying to find comfort in my religion or spiritual beliefs	
23. I've been trying to get advice or help from other people about what to do	
24. I've been learning to live with it	
25. I've been thinking hard about which steps to take	
26. I've been blaming myself for things that happened	
27. I've been praying or meditating	
28. I've been making fun of the situation	

SIGNIFICANT OTHERS SCALE (B)

NFER NELSON

Name: .....

Date: ..... **Record Number:** .....

Instructions

Please list below up to seven people who may be important in the individual's life. Typical relationships include partner, mother, father, child, sibling, close friends, plus keyworker. For each person please circle a number from 1 to 7 to show how well he or she provides the type of help that is listed.

The second part of each question asks you to rate how individuals would like things to be if they were exactly as they hoped for. As before, please put a circle around one number between 1 and 7 to show what the rating is.

Person 1 –	*Never*			*Sometimes*			*Always*
1 a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
2 a) Can you lean on and turn to this person in times of difficulty? ..	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
3 a) Does he/she give you practical help?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
4 a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
Person 2 –							
1 a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
2 a) Can you lean on and turn to this person in times of difficulty? ..	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
3 a) Does he/she give you practical help?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
4 a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
Person 3 –							
1 a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
2 a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
3 a) Does he/she give you practical help?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
4 a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7

PLEASE CIRCLE ONE NUMBER ONLY FOR EACH QUESTION